

“IF IT’S NOT BROKE, DON’T FIX IT”:  
PATIENTS’ AND CLINICIANS’ DECISION MAKING  
FOR TREATMENT OF END-STAGE RENAL DISEASE  
IN THE UNITED STATES

by

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Abstract

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This anthropological study investigated the sociocultural factors influencing access to kidney transplantation by tracking the nature of hemodialysis patients’ interactions with clinicians as they progress through their decision-making process for treatment of end-stage renal disease. This study focuses on patients’ decisions to remain on dialysis, and to decline offered cadaveric- and living-donor kidneys. Since patients’ decisions are influenced by their interactions with nephrologists and transplant professionals, this study also examined these healthcare professionals’ assumptions and values informing their decisions about communicating treatment options, and referring and evaluating patients for kidney transplantation. Ethnographic data were collected from one transplant center and six dialysis centers in Cleveland, Ohio.

Data on patients (n=79) and clinicians involved in dialysis, nephrology, and transplantation (n=29) revealed that a number of sociocultural factors influenced their decisions. There was a trend for African Americans to remain on dialysis while European Americans more frequently chose transplantation. Patients’ choice of treatment was largely based on their perceptions of current adjustment to dialysis and their current health status. Patients who chose transplantation primarily did so because they desired to leave dialysis. Patients who chose to remain on dialysis primarily did so because they felt relatively healthy and found little reason to



alter their status. They also feared undergoing transplant surgery, and had witnessed unsuccessful transplant recipients return to dialysis. Financial considerations were not a hindrance to seeking a transplant.

Data on clinicians' decisions reveal that nephrologists communicate to patients about ESRD treatment options progressively over time to maintain patients' hope. Nephrologists reported to refer patients in concert with the Medicare-established policy requiring annual review of patients. Noncompliance emerged as an important issue in nephrologists' decisions about referring and evaluating patients for transplantation because noncompliant patients may "waste" scarce kidneys.

Similarly, the transplant team placed all marginal patients on the waiting list unless their noncompliance (e.g., with dialysis) could not be remedied. Transplant professionals' decisions can thus be characterized as initially egalitarian and subsequently utilitarian in practice. Policy makers must consider the sociocultural factors affecting patients' and clinicians' treatment decisions to better facilitate patients' access to transplantation.

## PREFACE

I do not intend to characterize the field of medicine as a whole or to praise or criticize particular medical practitioners. Rather, it is my intention to demonstrate that medical practitioners and patients have different practical concerns that organize how they make treatment decisions. This research is as much about studying down as it is “studying up” (Nader 1974) in its focus on elites and centers of power in biomedicine. This study may be useful to people interested in social sciences and health-related fields, including anthropology, health care policy, and bioethics.

Before embarking on a cultural analysis, it is imperative to present a definition of ‘culture.’ According to Jenkins and Karno (1992:10),

“Culture can be defined as a generalized, coherent context of shared symbols and meanings that persons dynamically create and recreate for themselves in the process of social interaction. In everyday life, culture is something people come to take for granted—their way of feeling, thinking and being in the world—the unselfconscious medium of experience, interpretation, and action.”

This definition, which draws heavily upon Clifford Geertz’s definition of culture, is useful for this study for several reasons. First, encompassing the conception of “symbols and meanings” facilitates an understanding of the medical knowledge and practice examined in light of decision-making theory, since symbols are a model of and a model for people’s thoughts and actions.

Second, this definition moves beyond the cognitivist studies of culture as situated “from the neck up” (Csordas 1993). Notably, by viewing culture also as feelings, this definition provides the basis for understanding a broader range of experiences, such as dialysis patients’ emotions and bodily concerns that influence their decisions. Further, this definition accounts for an examination of moral values which underlie ethical decisions, as in the case of decisions about kidney transplantation. A culture’s normative system corresponds closely with emotion, which is

evident in the relation between *ought* and *feel* (Kitayama and Markus 1994). That is, one may feel honorable when doing what is considered as the “right” thing to do, or one may feel shameful or guilty when transgressing socially-established moral codes. Moreover, culture is here seen as a dynamic process, that may be contested by cultural members. This definition thus allows for an analysis of how cultural systems of norms, values, and ideas are reflected in sensual experiences, bodily habits, and everyday practices.

Since this study is a cultural analysis of decisions with ethical implications in the context of American biomedicine, is it also necessary to define ethics and morality. “Ethics,” in its most general sense, can be defined as “ways of understanding and examining the moral life” (Beauchamp and Childress 1994:4). Morals refer to normative values or social conventions, as construed within a given cultural context, about right and wrong human behavior (Beauchamp and Childress 1994:5).

There are several approaches to studying ethics, including normative and nonnormative ethics. Normative ethics seeks to determine the “general norms for the guidance and evaluation of conduct [that] are worthy of moral acceptance” and their merits (Beauchamp and Childress 1994:4). Ethical dilemmas thus involve the choice between adhering to one of at least two different “action-guides,” based on theories or principles, to resolve the problem.

By contrast, one form of nonnormative ethics, descriptive ethics, involves the “factual investigation of moral behavior and beliefs. It uses standard scientific techniques to study how people reason and act” (Beauchamp and Childress 1994:5). This anthropological study is also a study of descriptive ethics in its effort to determine which moral norms and values are expressed through health care professionals’ practices and policies that effect who gets access to the transplant waiting list.

A note about quoted statements: Phrases within brackets [ ] indicate that the words may not be precisely those used by the respondent, although they are quite close in meaning. In some instances, phrases within brackets explain the meaning of terms used by the respondent, e.g., ‘I came here [dialysis center] 2 years ago.’ Ellipses between statements within a quote indicate either that a pause or some form of verbal interaction occurred, e.g., the investigator asking for the subject’s clarification. These interactions are not always represented in the text in order to maintain the flow of the respondent’s statements. Such slight inaccuracies are the inevitable result of verbatim documentation of interviews which were not audio-tape recorded (Switzer, et al., 1997). All names are pseudonyms.

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## **LIST OF ABBREVIATIONS**

AAKP	American Association of Kidney Patients
DHHS	Department of Health and Human Services
ESRD	End-stage renal disease
HCFA	Health Care Financing Administration
HD	Hemodialysis
LTCP	Long term care plan
NKF	National Kidney Foundation
NOTA	National Organ Transplantation Act
OIG	Office of Inspector General
OPO	Organ procurement organization
OPTN	Organ Procurement and Transplantation Network
PD	Peritoneal dialysis
UNOS	United Network for Organ Sharing

## **CHAPTER 1: ANTHROPOLOGICAL THEORETICAL FRAMEWORK**

### **Aim and Scope**

While healthcare professionals view dialysis as a bridge to transplantation, many patients with end-stage renal disease (ESRD) live and die on dialysis because they do not have access to, or choose transplantation. In 1997, 38,236 patients with ESRD were registered on the National Transplantation Waiting List but only 11,409 (30%) received a kidney that same year (UNOS 1998a,b). Patients' decision making for treatment of ESRD is important for studying access issues because of the expectation that they would select transplantation given the financial and medical context of ESRD. Patients with ESRD are the only class of patients entitled by Medicare to treatment by either dialysis or transplantation. Kidney transplantation has been shown to significantly improve the quality of life of ESRD patients more so than hemodialysis (Evans, et al., 1985; Petrie 1989; Abram, et al., 1971; Simmons and Abress 1990). As well, transplantation is a more cost-effective means of treating ESRD than dialysis (Eggers 1992; Eggers and Kucken 1994; HCFA 1997; Caplan 1984). Why, then, do some clinically eligible patients not want a transplant?

Several researchers have found that access to transplantation has been particularly difficult for African Americans,<sup>1</sup> women, and the elderly, each to varying degrees, and for varying reasons, including immunological factors<sup>2</sup> and possibly socioeconomic prejudice (Kjellstrand 1988, 1990; Kjellstrand and Logan 1987; Greenstein, et al., 1989). While most studies examining ethnic differences in waiting times and receipt of transplants focus on

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<sup>1</sup> See Chapter 4 for a discussion of the cultural construction of "race" as it pertains to clinical and transplant literature.

<sup>2</sup> Pregnancy generally causes women to become sensitized to antigens from their babies, thus, donated kidneys are less likely to match immunologically.

biological and clinical data, very few have investigated patient preferences in their treatment decisions. Indeed, not every patient who is eligible for a transplant desires one.

Since healthcare decisions are made in a social and cultural context, the research examined the sociocultural and socioeconomic factors that motivate ESRD patients to choose dialysis instead of the most medically- and cost-effective treatment, transplantation. This study also compared factors influencing ESRD patients to choose kidney transplantation. To date, no anthropological studies have examined patients' access to, or ability to obtain a transplant.

Some scholars believe that financial issues are the primary motivations or barriers to seeking health care (Baer 1982; Singer 1986), and in this case, not wanting a transplant. Because Medicare covers 80% of dialysis costs indefinitely, and 80% of transplant costs for three years, ESRD patients have the financial basis to begin the process of obtaining either treatment. However, it may be the case that the limited time for which transplant costs are covered presents an economic challenge to some patients, as will be discussed later. But clearly, other, noneconomic factors need to be considered.

Cultural analyses of patients' medical decisions are at least equally, if not more, important as economic considerations in decisions about getting a kidney transplant. Patients' choices, I argue, are influenced by both formal and informal components of the health care system. Formal institutional features include: a) the administrative organization of a healthcare center, b) the clinical setting, c) the profession of medicine, d) policies, and e) the treatment activities themselves (Siminoff 1987).

Patients can be influenced through their interactions with any of these formal elements which have their own value system. In addition, this study focused on whether informal components -- sociocultural values and beliefs and interactional forces -- inform patients'

treatment decisions and ultimately their access to transplantation. This entailed elucidating how individual patients and nephrologists interacted within and manipulated the formal and informal legal and policy regulations that structure the access process. These and other factors affecting patients' treatment decisions can contribute to the differences seen by "race," sex, and age in the receipt of kidney transplants.

The anthropology of biomedicine is the topical area of this study of kidney transplantation because it is proposed that cultural values in biomedicine shaped the processes of decision making for patients and healthcare providers involved in the transplant process. This ethnographic study focuses on the decisions of patients and healthcare providers, specifically on the issues of: (1) how patients choose ESRD treatment modalities, (2) the sociocultural and economic differences between ESRD patients who prefer dialysis and those who prefer transplantation, (3) how nephrologists decide to educate and refer ESRD patients for transplantation, and (4) the process by which transplant professionals (e.g., surgeons, nephrologists, nurses, social workers) evaluate patients for transplantation. As will be discussed later in the chapter, decision-making theory, including goal theory, are used to explicate elements of patients' treatment decisions. Study techniques included interviews with patients, nephrologists, and transplant professionals, and direct observation of clinician-clinician and clinician-patient interactions.

The present chapter introduces the theoretical underpinnings of this study, including the anthropology of biomedicine, the anthropology of bioethics, anthropology of social identity, and decision-making theory. Chapter 2 details the research design and methodology of this study in a Midwestern city, Cleveland. Chapter 3 provides background information about dialysis and transplantation in the United States in terms of its clinical components, history, organization, and

structure. Chapter 4 reviews the literature on barriers to patients' access to kidney transplantation and sets forth a foundation for examining bioethicists' discourse on kidney allocation in light of cultural notions of justice. Chapter 5 paints a brief ethnographic picture of the roles of clinicians involved in caring for patients, the setting in which they make decisions about their patients, the daily routine of dialysis facilities, and the impact of dialysis on patients' lives. This background information provides context for understanding patients' and health professionals' treatment decisions.

The next five chapters are organized to provide the reader with a sense of the chronological process of the treatment decisions made by patients and health professionals as patients' renal disease becomes end-stage and they respond to this condition. Chapter 6 discusses nephrologists' decisions about communicating to patients regarding treatment options for ESRD. Chapter 7 focuses on the nature of patients' decisions about treatment for ESRD. Chapter 8 explores some additional treatment decisions that may actually hinder their access to transplantation.

Chapter 9 examines nephrologists' decisions about referring patients for transplantation, while Chapter 10 discusses how transplant professionals evaluate whether to register marginally suitable patients on the national transplant waiting list to receive a kidney transplant. Their decision-making process is examined in light of specific cultural values and notions of fairness. Chapter 11 concludes this study by outlining the implications of these findings for issues of access to health care, medical anthropology, sociocultural sequelae of ESRD, and decision-making theory.

The overarching theoretical framework is treatment decision making from an anthropological perspective. Psychological, historical, and medical levels of analysis are used to



supplement the dissertation framework to further explicate study findings. This diversity of analytic approaches, typical of the postmodern or present moment of qualitative research, is necessary because not all phenomena can be explained by a single perspective. As Laurel Richardson argues, the core feature of this moment “is doubt that any discourse has a privileged place, any method or theory a universal and general claim to authoritative knowledge” (1991:173 in Denzin and Lincoln 1994:2). This study intends to investigate occurrences where decisions may interfere with access to transplantation, and not necessarily offer resolutions to these dilemmas.

### **The Anthropology of Biomedicine**

Because kidney transplantation is a biomedical practice, it is imperative to review how biomedicine is culturally shaped to understand its organization and hence one aspect thereof -- the allocation process in the United States. This study is informed by theory from the anthropology of biomedicine.<sup>3</sup> Anthropology of biomedicine is a relatively recent field of inquiry, formed predominantly in the 1980s. Biomedicine, formally known as ‘Cosmopolitan’ or ‘scientific’ medicine, is the “preeminent professional ethnomedicine of Western cultures” (Gaines and Hahn 1985:18). Ethnomedicine is the comparative study of medical systems and of everyday understandings about health and illness with the aim of delineating their cultural underpinnings (Fábrega 1990:593; Nichter 1991:138).

Medical anthropologists studying illness representations in biomedicine may be divided into four general orienting approaches: (1) “illness representations as culturally constituted realities: the ‘meaning-centered’ tradition,” (2) “critical” medical anthropological perspectives

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<sup>3</sup> ‘Biomedicine’ (capitalized) is a general term used to denote the professional theory and practice of biological medicine (Gaines and Hahn 1985:18). The term was advanced by Gaines and Hahn and is now in standard use. It is used to contrast with various forms of medicine, e.g., Chinese, Ayurvedic, and Islamic medicine. The term ‘American biomedicine,’ is used here to indicate the U.S. variant of Biomedicine.

(CMA), (3) cognitive anthropology, e.g., cognitive models or “ethnoscience,” and (4) “illness representations as folk beliefs” e.g., the health belief model (Good 1994:25-64). Theoretical approaches to studying medical anthropology in general include the constructivist, embodiment, critical, ecological, and biomedical approaches (Gaines 1991).

Gaines (1991) coined the term “cultural constructivism” for his perspective that subsumes a variety of interpretivist approaches in the social science of medicine research. It draws from the work of Weber, Schutz, Mead, Turner, Geertz, and Freud, and also social psychology and the New Cultural History. Interpretive studies have included “hermeneutic,” “Kleinman’s school,” “meaning-centered,” and “semantic approaches,” among others. Cultural constructivism subsumes all of them. It differs from a similarly labeled perspective in sociology, called “social constructionism” (e.g., Wright and Treacher 1982; Berger and Luckman 1966), in the former’s emphasis placed on the concept of culture, which is examined from historical, interactionist, analytic, and semantic perspectives (Gaines 1991; 1992c).

Constructivists examine biomedical knowledge, organization, and practice as a sociocultural system within its cultural, historical, and social contexts (Kleinman 1980; Hahn and Gaines 1982, 1985; Hahn and Kleinman 1983; Gaines 1991, 1992a; Lock and Gordon 1988; Wright and Treacher 1982).<sup>4</sup>

Contrary to critical medical anthropologists’ contention that a cultural constructivist perspective is limited to the “micro” level (individual or local level) experiences of illness (Baer, et al, 1986), cultural constructivists investigate a range of related issues that extend beyond the clinical setting, to include so-called “macro” levels of analysis, e.g., cultural history, social organization, social interaction, and hierarchy (Gaines 1991). Other such “macro” issues cultural

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<sup>4</sup> This literature was greatly expanded upon by the following anthropologists: Ohnuki-Tierney 1994; Weisberg and Long 1984; Baer 1987; Stein 1990; Lindenbaum and Lock 1993; Gaines 1992c.

constructivists examine to interpret medical systems include studies of social classificatory systems, professional medical ideology, conceptions of person, and constructions of power (Gaines 1992c).

Contrary to a CMA perspective, Gaines notes that “power may be seen not as an empirical entity but [rather] as a dynamic cultural construct” (1991:225). Drawing upon Weber, Gaines defines power as “the ability to realize one’s will in an action in which others are participating,” pointing out that the means of realizing one’s will are cultural conventions, as are the forms of action, both of which change according to circumstances (1991:225). This perspective of power relations is helpful to understand the multivalent notions nephrologists maintain regarding their practices of information-giving, and both their and transplant professionals’ conceptions of and reactions to noncompliant patients.

Five key assumptions of the cultural constructivist perspective for medical anthropological research as set forth by Gaines (1991, 1992c) are as follows. First, “ethnomedical knowledge is problematic” (1991:240). That is, cultural constructivists “problemitize” or call into question the assumption that medical knowledge, organization, and practice are “found” in nature (1991:241). Thus, cultural constructivists view medical knowledge as a product of culture rather than as an “acultural scientific” knowledge base. Constructivist research does this by examining the underlying logic and assumptions guiding medical practice and the differences among and within specialties in medicine. Anthropologists have shown how biomedicine is not homogeneous in theory, practice, or organization; indeed, it is informed by cultural, political, and idiosyncratic factors (Gaines 1979, 1985b; Katz 1985; Hahn 1985; Lock 1985).

A second assumption of cultural constructivism is that “ethnomedical knowledge is constituted through embodied and disembodied discourse” (Gaines 1992c:22). That is, ethnomedical realities are created, defined, modified, and maintained via social interactions and communications (e.g., Kleinman 1980). This point is especially relevant to the polysemous concept of (non)compliance as will be discussed in Chapter 9. We will see, as Gaines proposes, that communication via embodied (speech) or disembodied (text) creates ethnomedical realities. As in the case of (non)compliance, it is the discourse about the reality, rather than the reality or phenomenon itself, that is the subject of some constructivist studies (see DeVecchio Good 1985).

A third assumption is that “an ethnomedical system is an unfinished product of culture history” (Gaines 1992c:23). Medical systems, including the part of the medical system that has evolved in its development and allocation of treatments for ESRD, are historically derived and always under construction. Thus, constructivists view medical systems in a processual rather than in a synchronic light (Gaines 1992c; Wailoo 1991; Brodwin 1996).

A fourth key assumption of cultural constructivism is that “ethnomedicines are constituents and expressions of their respective cultures” (Gaines 1992c:23; e.g., Lock 1995; Ikels 1997). As cultural beings, physicians, and their ethnomedical thoughts and practices, reflect and are grounded in lay cultural ideas. Even highly technological medical procedures have been shown to be culturally shaped, as is the case with dialysis (Alexander 1976, 1980). While biomedicine has aspects that transcend culture, it is culturally influenced where it is practiced. Both syncretism<sup>5</sup> and historical influences like colonization (Farmer 1992; Swartz

<sup>5</sup> Melville Herskovits defined syncretism in the following way: “...if we accepted the proposition that culture-contact produces cultural change, and that cultures of multiple origin do not represent a cultural mosaic, but rather become newly reintegrated, then the next essential step was to ascertain the degree to which these reconciliations had actually been achieved, and where, on this acculturative continuum, a given manifestation of the process of reworking these elements might lie” (1941:xxii-iii in Shaw and Stewart 1994:5-6). This definition has

1992; Brodwin 1996) shape biomedical theory and practice, resulting in its many versions (Payer 1988).<sup>6</sup> More recently, DeVecchio Good (1995:461) posits that cultural studies of biomedicine should “focus on the dynamics, tensions and exchanges between these local and global worlds of knowledge, technology and practice.” As will be shown, global and historical forces have shaped patient selection for transplantation in the US.

The last core assumption of cultural constructivism is that “ethnomedicines concern human, experience-near realities” (Gaines 1992c:24). Constructivist approaches analyze ethnomedical systems in human experiential terms, e.g., pain, suffering, relief, fear, etc. Constructivists seek to understand the intersubjective reality of those involved in ethnomedicine by including the voices of patients and healers (Gaines and Farmer 1986; Gaines 1992c; Kleinman 1988; Kleinman and Kleinman 1990).

An alternative school of thought in medical anthropology, the critical medical anthropology perspective, “understands health issues in light of the larger political and economic forces that pattern human relationships, shape social behavior, and condition collective experience, including forces of institutional, national, and global scale” (Singer 1986:128). This perspective argues that illness is the manifestation of global political, economic processes. Critical medical anthropologists generally identify themselves by this label and contend that

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been criticized for assuming that syncretism occurs in a mechanistic manner whereby people acculturate progressively moving along a continuum, yet in contrast, “syntheses, adaptations, assemblages, incorporations or appropriations are renegotiated and sometimes denied and disassembled” (Shaw and Stewart 1994:5-6).

<sup>6</sup> Various forms of Biomedicines in different cultural contexts include: ‘American’ Biomedicine (Gaines and Hahn 1982; Hahn and Gaines 1985; Lock and Gordon 1988); Taiwanese Biomedical practice which vary among ‘Chinese-style doctors’ and ‘Western-style doctors’ (Kleinman 1980); German naturopathic (Maretzki 1992; Townsend 1978); French Biomedicine (Gaines 1992b; Hershel 1992; Herzlich 1973); Latin American Biomedicines (Finkler 1991; Scheper-Hughes 1988; Low 1985); Italian (Gordon 1994; Gordon and Paci 1997); Greek (Blue 1992); Israeli (Pliskin 1987); Haitian Biomedicine (Farmer 1992; Brodwin 1996); and Japanese Biomedicine (Norbeck and Lock 1987; Ohnuki-Tierney 1984; Long 1984; Lock 1980).

studies of “macro” (global economic) level processes are the “missing link in medical anthropology” (Morsy 1979).

Critical medical anthropologists maintain several approaches to research in medical anthropology. The following review of these approaches draws upon the classification as set forth by Gaines (1991, 1992c) and Morgan (1987). Most critical medical anthropological views fall under the rubric of political economy of health (Gaines 1992c). One such group are the Marxists who contend that medicine must be examined within the context of “capitalism” (see Morgan 1987; Singer 1986). Marxists argue that medical knowledge is a reflection of capitalist ideology and thus medicine serves as an instrument of control and domination for the capitalist class (Morgan 1987; Singer 1986; Waitzkin 1979, 1980).

Another group of political economists are those who ascribe to “Dependency theory” (Gaines 1992c). They believe that illness is caused by poverty, underdevelopment, and maldistribution, which are caused by penetration of capitalism, imperialism, and colonialism from “core” developed countries into the world’s “peripheral” developing countries (Baer 1986; Baer, et al., 1986; Singer 1986). They also contend that for one area to develop in its health, another must become underdeveloped (Morgan 1987:136).

Political economists also espouse the view of the “Hegemony of Biomedicine” (Gaines 1992c). They criticize Biomedicine for destroying traditional healing systems by introducing new diseases to colonized people (Morsy 1978, 1979; Frankenberg 1988). As Rhodes succinctly put it, proponents of hegemony “regard biomedicine’s aura of factuality as precisely its source of power” (1990:168).

Another form of political economy, which Gaines calls the “cultural critique of medicine,” criticizes medical practices and organizations for causing health problems (Gaines

1992c; see Ehrenreich and Ehrenreich 1970; Illich 1976; Stebbins 1986). Proponents of this perspective attribute illness to economic and political factors (e.g., “racism” and “sexism”) inherent in industrial society but not to capitalism *per se* (Illich 1976). Some argue that medicine “supports and replicates the status quo by keeping women and minorities subordinate” (Morgan 1987:133). Proponents are in favor of reform in health policy, and see it as possible within a capitalist system, to enhance effectiveness of health care delivery.

A form of critical medical anthropology not aligned with political economy of health, “critical theory,” takes an approach much like cultural constructivism to focus on macro-structural issues and the role of power in society and Biomedicine (Gaines 1992c; e.g., Lock 1986 in Gaines 1991). Accordingly, the body and its illnesses reflect culturally constructed conflicts of social and economic relations (ethnicity, gender), rather than capitalism *per se*. Thus, sickness is a reflection of the “indignities of postindustrial life,” exploitation, and oppression (Scheper-Hughes 1988, 1990; Scheper-Hughes and Lock 1987; Gaines 1991).

Since problems with CMA are multiple and were detailed and explicated at length by Gaines (1991), only a few key problems that he points out are noted here. First, various CMA perspectives maintain acultural and ahistorical views of medical knowledge. CMAs accept as naturally given and as value-neutral, the positivist theory of universal diseases, as espoused by American and other Biomedicines. While CMA views do not problematize medicine’s labels or nosologies, they do differ from American Biomedicine in their notions of disease etiology.

The second problem with the CMA perspective is its materialist focus in which capitalism is seen as the primary cause of sickness. CMAs consider sickness to be caused by “macrolevel” and “external” (to individuals) forces of “capitalism,” “the modern world capitalist system,” “social structure,” “class,” and “power relations” (Singer 1986; Baer 1982; Waitzkin

1980). For example, Waitzkin writes: “the Marxist viewpoint questions whether major improvements in the health system can occur without fundamental changes in the broad social order” (1980:333). Gaines (1991) points out that Waitzkin (1980) and Elling (1977) both consider medicine and health to be effected fundamentally by the “capitalist world system.” Such materialist theories of disease etiology assume that healers are motivated by malevolent motives dictated by structural inequities (Gaines 1992c). Further, CMA research fails to account for ecological factors contributing to illness and disease concomitant with agriculture and settlement (Gaines 1991). Lastly, it is important to point out that CMA research excludes aspects of human experiences, e.g., persons, social interaction, meaning, emotion, history, and local-level realities.

Cultural constructivism is a helpful tool for examining or deconstructing patients’ treatment decisions that are shared by members of different ethnic groups. The relationship between cultural constructivism and treatment decisions can best be described in the following ways. It is proposed here that the values and beliefs about the body, illness, and health shared by members of ethnic groups will inform their treatment decisions. Thus some treatment decisions will be interpreted in terms of cultural constructions of the body and illness. Some decisions will be interpreted by contextualizing them within historical events. Patients’ treatment decisions are also examined in light of experience-near concerns about fear, suffering, pain, etc.

This study uses the cultural constructivist perspective as a tool also for analyzing and deconstructing the knowledge and practice of nephrology and transplantation. This involves examining the shared system of meanings held by healthcare professionals informing their decisions about: 1) information-giving, 2) referring patients to transplantation, and 3) patient eligibility for kidney transplantation. On its face, one might consider some of the political



economists' perspectives to be useful tools for analyzing subtle barriers to access to transplantation, including: 1) nephrologists' control of information provided to patients about treatment options, 2) the power relations between patients and healthcare professionals expressed through the idiom of 'compliance,' and 3) financial constraints of transplant centers. However, upon closer examination, we will see in Chapters 6-10 that socioculturally shared meanings about the emotional impact of "information" on patients and personal responsibility for health inform healthcare professionals' decisions. In addition, concerns about the livelihood of the transplant center are central considerations informing transplant professionals' decisions.

Although financial constraints may factor into some patients' choices of treatment, they are not necessarily the sole driving force in patients' treatment decisions. This issue is taken up in Chapter 7. As will be seen, financial issues are not paramount for patients. They do play a role, however, in some clinicians' decisions. Since limited finances are examined as experience-near or local level realities that patients and physicians must contend with, this study is more closely aligned with the perspective of cultural constructivism.

Because there are many equally acceptable ways of allocating organs (Kilner 1990), transplantation and access to it are bioethical issues. Further, because the morals that guide each 'fair' choice or method of allocating kidneys are steeped in cultural values, the bioethics of kidney transplantation must be examined in its cultural context. As a consequence, we need a grounding in bioethics.

### **The Anthropology of Bioethics**

The discipline of medical ethics or 'bioethics' emerged after World War II and blossomed in the 1960s. Bioethics is the process of identifying and resolving conflicting moral judgments in patient care or clinical research in the context of Western biomedicine (Beauchamp and Childress

1994; Fábrega 1990). As a branch of moral philosophy, biomedical ethics has become an anthropological field of inquiry. The nature and deliberation of bioethical issues have been demonstrated to be grounded in cultural understandings about right and wrong. Since the 1990s, anthropologists (Lieban 1990; Young 1990; Marshall 1992; Muller 1994; Fox 1990; Kunstadter 1980; Ikels 1997) have explored the field of cross-cultural bioethics. Lieban (1990) coined the term ‘ethnoethics’ to denote the exploration of ethical issues in medical care in non-Western societies, which includes:

“moral norms and issues in health care as understood and responded to by members of these societies. Ethnoethics should be informative not only about cross-cultural variation in ethical principles of medicine, but also about variations in the issues which in different societies become defined as morally relevant or problematic. Ethnoethical information should contribute to the discourse on medical ethics not only by illuminating culturally distinctive moral views and problems, but also by helping to provide a more realistic and knowledgeable basis for the exploration of cross-cultural ethical similarities” (1990:223).

Few bioethicists, in contrast, have paid attention to the social and cultural contexts of health care decisions (see Pellegrino, et al., 1992; Veatch 1989; Fox and Swazey 1984; Fox 1990). Bioethicists tend to accept as given certain Western philosophical assumptions at the point of departure in analyses of bioethical issues. In contrast, medical anthropologists and some medical sociologists examine the cultural foundations of bioethical practices by calling into question the very philosophical bases that bioethicists take for granted. Medical sociologist Renée Fox (1990) identifies the philosophical assumptions bioethicists tend to make:

“From the outset, the conceptual framework of bioethics has accorded paramount status to the value-complex of individualism, underscoring the principles of individual rights, autonomy, self-determination, and their legal expression in the jurisprudential notion of privacy” (1990:206).

Because the American definition of person as ‘individual’ permeates bioethics, bioethicists tend to downplay other values such as “decency, kindness, empathy, caring, devotion, service, generosity, altruism, sacrifice, and love” (Fox and Swazey 1984:355). Anthropologists can therefore contribute to the field of bioethics by

“calling attention to the cultural underpinnings that sustain and reinforce ethical constructs in matters of health and illness and by extending the scope of the field through explorations of cross-cultural and intracultural variation in the production of and responses to medical and moral dilemmas” (Marshall 1992:62).

Chapter 4 describes in greater detail the philosophical theories and policies related to the allocation of scarce resources, e.g., patient selection for kidney transplants, and their cultural underpinnings.

Anthropologists have examined a wide range of bioethical issues cross-culturally.<sup>7</sup>

Fruitful related bioethical issues of anthropological inquiry have been organ donation and transplantation. Since this study will contribute to that domain, a review of their literature is presented below.

### **The Anthropology of Organ Transplantation and Dialysis**

Anthropological studies of organ donation and transplantation have been conducted primarily in Japan (Lock and Honde 1990; Lock 1995, 1996; Ohnuki-Tiemi 1994), and in the US (Joralemon 1995; Sharp 1995), and to a lesser degree in China (Ikels 1997; Woo 1992) and Sweden (Machado 1996; Sanner 1994). Anthropologists have examined the cultural values, symbols, metaphors, and issues of reciprocity involved in transplantation. Most of these studies examine cultural attitudes about and practices of organ donation, concentrating on two major interrelated themes: a) cultural bases of definitions of death, and the meaning of the technology involved in defining death, and b) cultural perspectives of organ donation in terms of reciprocity, and relationships between recipients and donors.

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<sup>7</sup> Studies of cross-cultural bioethics include: research bioethics in Egypt (Lane 1994), female genital surgeries (Lane and Rubinstein 1996; Daniel Gordon 1991); informed consent (Kaufert and O’Neil 1990; Harth and Thong 1995), reproductive ethics in Canada (Kaufert 1990), the use of interpreters in health care (Kaufert and Putsch 1997); clinical ethics consultations in the US (Orr, et al., 1995), end of life decision-making (Muller and Koenig 1988; Muller 1992; Ventres, et al., 1992; Kaufert and Locker 1990), truth-telling of diagnoses of cancer (Gordon 1990, 1991, 1994; Gordon and Paci 1997), and the ethics of “racial” classification (Gaines 1995).

Research in the US has focused on the nature of gift-giving relationships between organ recipients and donors, their interactions with transplant professionals, and the medically based, yet culturally shaped, ideology about altruism (Sharp 1995; Joralemon 1995; Fox and Swazey 1978, 1992; Abrahams 1990). An account of research on transplantation would be inadequate without acknowledging the seminal work of medical sociologists Renée Fox and Judith Swazey (1978, 1984, 1992). Fox and Swazey identified the ethos of American transplantation as a 'courage to fail' value system that was particularly apparent among transplant and artificial organ pioneers, as shown in the following passage:

"This ethos includes a classically American frontier outlook: heroic, pioneering, adventurous, optimistic, and determined. It also involves, however, a bellicose, 'death is the enemy' perspective; a rescue-oriented relentless, hubris-ridden refusal to accept limits" (1992:199).

Fox and Swazey were the first to interpret the kidney recipient-donor relationship in terms of Marcel Mauss's (1954) paradigm of the gift-exchange relationship in the US. They found that recipients and donors get caught up in the 'tyranny of the gift' explained as follows:

"There is a fundamental sense in which the recipient can never repay the donor for offering a gift of life that is a vital part of his or her bodily self. As a consequence, donor and recipient may find themselves psychologically and sociologically locked in a creditor-debtor vise that binds them to one another in a mutually fettering way. Because a part of him(her)self is inside the recipient, the donor may feel impelled to watch over the transplanted kidney and the life of the individual who now carries it. The recipient, in turn, may feel that his (her) debt to the donor is so enormous and unrepayable that the donor has the right to ask anything and to participate illimitably in his (her) life" (Fox, et al., 1984:56).

Fox and Swazey also found that US transplant professionals have a tendency to minimize the personal side of the gift aspect of transplantation through "commodification" and "marketification" of organs (1992:207). They explain how the 'de-gifting' of transplantation implicit in this market approach has been accompanied and reinforced by the progressive 'biologization' of donated organs which occurred during the 1980s and early 1990s. Most notably,

“organs are being thought of as ‘just organs,’ rather than as living parts of a person, offered in life or death to sustain known or unknown others, that resonate with the symbolic meaning of our relation to our bodies, our selves, and to each other, and with the more than fleshy significance of what has been given and received...” (Fox and Swazey 1992:207).

So while the transplant industry perpetuates organ donation through a marketing theme of ‘gift of life,’ it does so at the cost of the humanity of relationships reinforced through gift-giving. To support their contention, Fox and Swazey point to the terminological transition demarcating this biologization of selves: living parts are now seen as human body parts (1992:207).

More recently, anthropologists have further analyzed the gift-giving relationship (Sharp 1995; Joralemon 1995). They find that the ideology about altruism is contradictory: human body parts are considered as both objectified and personalized parts. Transplant professionals help recipients adjust to their new organs and lifestyle by promoting the view that organ donation is an altruistic, selfless act requiring no reciprocity. Body parts are objectified to enforce this message, through the use of euphemisms like ‘harvest’ and ‘procure.’ On the other hand, cultural rhetoric promotes the perception of organs as personalized parts, expressed as ‘a part of the donor lives on in the recipient.’ Consequently, when recipients psychologically identify and develop fictive kin relations with donors, transplant professionals consider such behavior pathological, although they contradictorily maintain some of these notions of fictive kin. Transplant professionals hold these contradictory views because they wish to protect the privacy and anonymity of donors due to the potential for the donor and recipient to engage in the “tyranny of the gift,” as described above. Moreover, the development of such a fictive kin relationship undermines the ideology of organ donation as a voluntary “gift of life.” Interestingly, such contradictory messages promoted by transplant professionals are mirrored in the views held by dialysis staff toward kidney patients (Alexander 1976, 1980).

The cultural underpinnings of organ donation have also been examined in other cultures. In Japan, for example, many people object to organ donation because it violates Japanese Buddhist practices of ancestor worship and social practices of reciprocity. Grounded in Buddhist practice of 'ancestor worship,' deceased family members are transformed into ancestral spirits and must be respected and appeased (Lock, et al., 1993). Ancestors suffer (and consequently the extant family) if their corpses are incomplete as they would be if there had been a donation.

Japanese social practices dictate that it is socially unacceptable to take things (e.g., organs) from others; there is no tradition of altruism in Japan as there is in the US (Lock and Honde 1990). Since gift-giving in Japan is grounded in a framework of reciprocity, organ recipients are in an awkward situation because they are obligated to repay the donor but cannot (Lock, et al., 1993:31). The Western values of individualism and autonomy, inherent in imported transplant policies and technology, also challenge traditional Japanese cultural values.

In China, (Ikels 1997; Woo 1992) one major ethical issue in dialysis and transplantation is the fact that only the independently wealthy or those few with health insurance can afford access to renal therapy. Chinese society questions whether it should channel many resources to such a small percentage of the population through expanded insurance coverage (macro-allocation). China also has a low donation rate from both cadaveric and living-donors for cultural reasons.

Live-donors may be reluctant to donate because 'vital essence' or the 'material basis of life' is stored in the kidney and can be transformed into *qi*, but without it, the body's structural and functional integrity is threatened (1997:1275).

Cadaveric donors are likewise hard to find because of Confucian beliefs which, like the Japanese concept of filial piety, require relatives to return the deceased's body intact to the

ancestors to traverse the underworld. Without their organs, ghosts may retaliate against those who authorized donation. In addition, ghosts do not rest until buried; but until that point, they remain in an agitated state amongst the living who may incur the wrath of the ghost. The absence of legal criteria to define brain death also prevents organ donation.

A noteworthy public health study examined social and cultural factors affecting Aborigines' and Torres Strait Islanders' treatment outcomes for dialysis and renal transplantation in North Queensland (Bennett, et al., 1995). In-depth interviews with kidney recipients (n=11) revealed that continued alcohol consumption and the separation from kin and country were significant factors leading to poor outcomes and reluctance to continue medical treatment. Many rural patients had to alter their lifestyles by moving to urban areas to receive dialysis therapy and maintain immunosuppressant therapy. The change in lifestyle was stressful to patients because it involved separation from family, a change in food options, and financial strains.

The study by Bennett and colleagues is particularly interesting because the Aborigines and Torres Strait Islanders have comparable problems of access to transplantation as do African Americans. Both groups of people experience ESRD at significantly higher rates than the national average; it is 10 times higher among Australian Aborigines, and it is 4 times higher among "black" than "white" persons (HCFA 1997:13). The main causes for both groups are chronic glomerulonephritis and diabetes. Both groups remain on the cadaveric waiting list almost twice as long as European Americans.

Further, Aborigine to Aborigine and African American to African American transplants are uncommon because of cultural, ethnic, or religious beliefs that limit cadaveric donations (see Chapter 4). Moreover, living donations among both groups are limited because of the high prevalence of diabetes in both groups. The only notable difference between the two groups is

financial: whereas the price of maintenance immunosuppression drugs is heavily subsidized in North Queensland (Bennett, et al., 1995:613), 80% of the costs (for the three most expensive immunosuppressant drugs) are covered for only three years in the US. While Aborigines must pay approximately \$15.00 for each drug per month, African Americans must pay between \$1,000 to \$2,000 per month after the three year mark, not to mention 20% of the costs prior to that time.

Only one anthropologist, Linda Alexander (1976, 1980), has conducted ethnographic research on dialysis patients to explain the exceptionally high rate of depression and suicide in that population. Drawing upon the double-bind theory, as originally expressed by Gregory Bateson (1956:175), Alexander posited that pathogenic behavior disorders arise if six criteria are met within a complementary relationship between parties who express or exchange differing kinds of behavior. Dialysis patients experience double-bind relationships with their healthcare providers (technicians and nurses) at the dialysis unit because they are told to be: 1) independent, 2) normal, and 3) grateful, which patients cannot do due to their illness and/or interactions with the staff. First, while the staff expected patients to do much of their own treatment monitoring,<sup>8</sup> patients were unable to do so because they were too sick and/or tired. Yet patients who complied with staff's directives and monitored their own treatment 'depended' on the staff to acknowledge their independent behavior. Without this acknowledgment, patients experienced rejection and abandonment by staff.

Secondly, dialysis and kidney disease disrupted a person's normal life in various areas, such as in relationships, employment, economic, recreational, sexual, and physical domains. Patients were not normal because they were sick. But the staff expected patients to become normal by responding positively to their manipulations of the patient's drugs, timing of dialysis,

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<sup>8</sup> This is no longer an expectation today, but it is encouraged.



etc. Staff expected patients to find employment, find a place to live, and resume pre-dialysis activities. But by having to manipulate the patient's disease to make them better, the staff implicitly told patients that they were really not normal.

Lastly, when the staff tried to help patients, staff became upset if patients did not accept this help, because it meant that patients were not grateful for it. When the staff helped patients who were slow in their treatment monitoring, they infringed on patients' attempts to be independent, and consequently, patients failed to be grateful for this infringement.

No anthropological studies have examined the other side of the transplant experience -- patients' access to transplantation. As we will explore in greater detail in Chapter 4, access to transplantation is difficult for many people because there are fewer kidneys available than the demand for them. Bioethicists use the term "microallocation" to describe the process of distributing scarce resources in a socioculturally defined "fair" way. There are several formal mechanisms of allocating kidneys: patient referral, patient selection, and distribution of donor kidneys.

This study focuses on the first two steps because they involve decisions on the part of nephrologists and transplant professionals about selecting the best candidates for kidney transplantation. An analysis of kidney allocation, e.g., the UNOS algorithm and point system established for matching available kidneys to wait-listed patients, is not included here because it does not involve decisions on the part of clinicians on a daily basis.

As I will show in Chapters 9 and 10, an anthropological perspective on access to transplantation can reveal the cultural assumptions that contribute to partiality in the referral and evaluation of patient candidates for kidney transplantation. Cultural values in biomedicine, drawn from different ethnic values within the US, become apparent in the decision-making

process of clinicians and patients. Thus, before reviewing the theoretical approaches social scientists use to examine decision making, a brief description of the anthropological approaches to studying social identity in the US will be presented below.

### **The Anthropology of Social Identity: The Concepts of Ethnicity and “Race”**

#### **Definitions of ethnicity**

Since this study sought to explain the low rate of kidney transplantation among African Americans as a matter of ethnic identity, (rather than of biology, as clinicians contend, which will be examined in Chapter 4), it is essential here to define “ethnicity” in its general sense and specifically how it is used within the US. An “ethnic group” can be defined as:

“a self-perceived inclusion of those who hold in common a set of traditions not shared by others with whom they are in contact. Such traditions typically include “folk” religious beliefs and practices, language, a sense of historical continuity, and common ancestry or place of origin (De Vos 1995:18).

De Vos (1995) explains that social identity tends to be based on one of three orientations: future, present, and past. Social identity can be “future-oriented,” based on common interests in a future goal, e.g., political and religious movement or social causes. Social identity can also be defined through “present orientation,” e.g., loyalty to one’s profession and social status. In contrast to other forms of social identity, ethnic identity is primarily a “past-oriented” form of identity, based on perceived ancestry and origin.

People identify their ethnicity through a variety of locally important features, including:

- 1) “racial uniqueness” or a sense of genetically inherited differences;
- 2) territoriality or a tradition of territorial or political independence;
- 3) economic bases or economic autonomy;
- 4) religion;
- 5) aesthetic cultural patterns which are used symbolically as the basis of self and social identity; and
- 6) language, including dialects (De Vos 1995).

Ethnic identity is a continually evolving social process. Social or ethnic identity is reified through interactions and comparisons to both others within one's ethnic group and others outside of it (Twine 1996). A contrastive sense of ethnic identity often springs from or is fortified by a chronic condition of conflict in pluralistic societies (De Vos 1995; De Vos and Romanucci-Ross 1995; Mead 1995). Commonly, the forces of oppression lead many less advantaged people to reaffirm their ethnic identity as a way of self-valorization (Roosens 1989:14; Mead 1995).

The difference between culture and ethnicity, which is often confused, is well expressed by Roosens:

"ethnicity can only be manifested by means of cultural forms that give the impression that they are inherent to a particular category or group of individuals. It is impossible for ethnic identity to mean anything without the existence of ethnic groups or categories, for it is a relational construct" (Roosens 1989:19).

### Ethnicity in the US

The US is a pluralistic society, meaning that it has a diversity of ethnic groups. The diversity is a result of mass immigration by Europeans initially, then others throughout the world continuing today, and the institution of slavery. Objectively defining ethnic groups and/or minority groups is the subject of heated debate among US Anthropologists (see American Anthropological Association Newsletter 1998). The US folk model of ethnicity accords "white, northern European Protestants" as having no ethnicity (Banton 1983:146 in Banks 1996:68) owing to their dominance (in social status in the Weberian sense). Thus, "the core definition of American identity, as white, Caucasian and blonder rather than darker" (Mead 1995:304) is rarely contested perhaps because, as a "racial" identity, Americans find it difficult to challenge their constructed biological conceptions. People's ethnicity in the US often incorporates aspects of "racial" identity (discussed below) (Blu 1980; Sunderland 1997).

While all people can be said to fit within some ethnic group, however large or small its constituency in the US, the identity of various groups has changed over time (Barrett and Roediger 1997). Today, ethnic groups include, for instance: African Americans, Japanese Americans, Chinese Americans, Native Americans, Mexican/Hispanic/Latin Americans, Irish Americans, Jewish Americans, Russian Americans, Polish Americans, Italian Americans, Anglo-Saxon Americans, German Americans, etc. Increasingly, ethnic groups, e.g., African Americans, are affirming their identity via political and religious affiliations which underscore their Americanness (De Vos 1995).

It is important to point out that there may be variations in values held within ethnic and religious groups due to subcultural differences (Murray 1992:36). For instance, some subcultural groups may exist on the basis of geographical location in the US, residence in the inner city or suburbs, degree of religiosity, socioeconomic status (Twine 1996), etc. Ethnic identity intersects with other forms of social identity, such as caste or class. According to Margaret Mead (1995), the US maintains a caste system in reference to African Americans. Specifically, Mead contrasts the caste attitudes in the South, “which approve physical and emotional closeness as long as social distance is maintained,” with caste attitudes in the North, “which will concede some political and economic equality as long as spatial distance is maintained” (1995:308).

Since African American ethnic identities are a central feature of this study, it is essential to outline some key features that unify people under that label. This is by no means a comprehensive review, but rather an introduction to some of the common features of African American ethnic identity. A large body of historical and social science literature considers African Americans as an ethnic group in the US (see Whitten and Szwed 1970; McAdoo 1997).

According to De Vos (1995), African Americans are “redefining themselves in ethnic terms” and explains why this is a relatively recent development:

“Among blacks brought in as slaves, African ethnic traditions persisted only as submerged fragments. Now, however, black Americans are reaching back to a pan-African heritage to create an ethnic tradition of their own, separate from that of Europeans and Asians. They are trying to recreate their identity on the basis of cultural continuities rather than on the simplistic caste-racial criteria used in oppressing them. Blacks are seeking means of amplifying all the criteria comprising ethnicity. Territorial origins in Africa; and territorial and economic strongholds in present American settings; old folk and religious practices; and features of life-style, family relationships, and artistic traditions are being scrutinized for their Afro-American flavor” (1995:29).

Myriad shared cultural traits define African Americans as such, including a common: history of slavery, segregation, racist oppression; language or dialect (Kochman 1970); matriarchal and multigenerational family structure (Stack 1970; Sudarkasa 1997); aesthetics, e.g., “soul food” (Hughes 1997), soul music and the blues (Haralambos 1970); and religion, e.g., Christianity and more recently, cultural exposure to Islam (De Vos 1995).

A fascinating article examining the ethnic identity of “biracial” (African American and European or Asian ancestry) college women points up some key aspects of “black” and “white” ethnic identity (Twine 1996). Twine found that these women had shifted their identity from “white” to “black” upon involvement in a highly politicized racial environment at the University of California at Berkeley. Components of the “white” identity that they shed included a neutral or nonexistent sense of “racial” identity, middle class socioeconomic status, a focus on being individualistic, and feeling comfortable among other “whites.”

In contrast, the aspects of “black” identity that these women self-incorporated through social involvement with other “blacks” at college included, self-censorship with “whites” and a greater awareness of the possibility of “racial” discrimination (though none had previously experienced it). While their “black” friends maintained suspicion and social distance with “non-blacks,” these women maintained their “comfort zone” when interacting with “whites”

(Twine 1996). Essed (1991) points out that individuals who self-identify as “black” learn from their family when they are young to maintain suspicion and social distance with “non-blacks” to survive in a “white” dominated society.

Different subcultures among African Americans exist in at least two ways. Notably, African Americans from the South culturally differ from those in the North (Hine 1996). Yet many Northerners, who have themselves, or their recent predecessors have migrated from the South, have maintained some Southern traditions (Goings and Mohl 1996). There may also be differences among African Americans who live in the inner city versus those who live in suburbs, or between genders (McAdoo 1997; Spelman 1988).

In the US, African Americans are conceived by lay persons as members of one “race.” The use of “race” is especially problematic in scientific studies, including clinical studies that examine health differences by “races,” because it is not a scientific category. This dissertation draws upon many clinical studies of ESRD demographics, rates of, and access to dialysis and transplantation, virtually all of which compare “racial” groups. Such studies assume that different “racial” groups have a different biological or genetic make-up. In addition, these studies use terms denoting “race” and ethnicity interchangeably, e.g., “black” and “African American,” reflecting a confusion between culture and their notion of biology. It is likely that such studies use “race” in a way similar to how many geneticists and physical anthropologists use it, to denote

“a population which differs in the incidence of certain genes from other populations, with one or more of which it is exchanging or is potentially capable of exchanging genes across whatever boundaries (usually geographic) may separate them” (Montagu 1974:11).

The clinical studies’ conclusions about “racial” differences are unfounded because the concept of “race” is a cultural construction of social identity (Montagu 1963, 1974; Boas 1966; Gaines

1992b, 1995). The following examines what is meant by the cultural basis of “race” and then outlines the US concept of “race.”

### Definition of “race”

Conceptions of “race” vary cross-culturally. In the US, “race” popularly refers to membership in socially defined groups as well as biological ones (Watts 1981). In the US, the nonbiological criteria used to identify “races” are arbitrary: they are applied to people from different geographic regions (e.g., Asians, Orientals), continental areas (e.g., African, [Native] American), languages (e.g., Hispanic), and religions (e.g., Jews, Christians, Muslims) (Watts 1981:10; Gaines 1995; Blu 1980). Putative skin color (white, black, red, yellow, brown) is also used as a biological category for classifying people (Gaines 1995). In contrast, French identity is accorded to those who have adeptly acquired the French language, while German identity is accorded to those who can trace their heritage through German “blood” (Gaines 1995). Another poignant example is that children of “black” and “white” parents are considered “black” in the US, but in Brazil, one drop of “white” blood renders a person neither “black” nor “white,” but “mulatto” (Degler 1971).

Gaines (1992b) posits that American biomedical practitioners and many Americans alike ascribe to what he calls the folk biological theory of “race” whereby “racial” differences are seen as a result of biology rather than being socially produced. “The U.S. version of folk biogenetics assumes behavioral, and/or biological homogeneity within categories and assumes the categories to be reflections of nature rather than culture” (Gaines 1992b:187). Practitioners of American biomedicine have been found to make diagnostic and treatment decisions on the basis of patients’ social identity, such as “race,” class, or sex (Lin, et al., 1986; Lock 1985; Peterson, et al., 1994; Todd, et al., 1993; Jones 1981).

The reliance on biology to explain social difference can be explained in terms of biology being a “key symbol” embodying polysemous notions of science, progress, and empiricism in American biomedicine (Gaines 1992b:199-189). In Chapter 4, the assumption that “races” represent biologically different groups of people is analyzed further in light of the clinical studies examining treatment choices for ESRD and problems involved in access to transplantation. A cultural constructivist perspective will allow for the deconstruction of US concepts of “race” in transplant medicine.

Deconstructing “race” is important for setting the stage to examine treatment decisions as a matter of culture rather than biology. This study examines patients’ treatment decisions in terms of ethnic differences, rather than in terms of the biologically-based notion of “race” as used by clinical studies. Thus, different treatment decisions by the study sample are explained in terms of ethnic values and beliefs. The study sample is therefore analyzed for differences in ethnic identity rather than putative “racial” categories. By showing that treatment choices are informed by ethnic and cultural beliefs and values, we can then conclude that problems with access to transplantation are partly a matter of the interplay between culture and individual choice. Given the constructed nature of “race,” all references to “race” used by clinical (and sociological) studies will be set in quotations.

### **Decision-Making Theory and Physician-Patient Communication**

Various academic fields investigate different aspects of decision making according to questions relevant to their field.<sup>9</sup> Within all fields, research into decision making is, at heart, a

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<sup>9</sup> In medicine, decision making has been investigated from both physician and patient perspectives. Guided by the legal and ethical concerns with informed consent, much of the research on patients’ decision making is devoted to determining patients’ preferences regarding: a) the extent to which they wish to participate in treatment decision making (Margalith and Shapiro 1997; Degner and Sloan 1992; Strull, et al., 1984; Ende, et al., 1989); b) the presentation or “framing” of information about given treatments (Hux and Naylor 1995); c) physicians and health care plans (Eastman 1997); and d) available medical treatments (Ciampi, et al., 1982; Meyer, et al., 1995). Studies examining patients’ choice of medical treatment, for instance, include treatment decisions about cancer (Ciampi, et



study of reasoning or “rationality” (Gaines 1993; Good 1994; Garro 1998). Studies of decision making fall within one of two schools of thought: normative and descriptive. Normative theorists assume that individuals are rational actors, who are prompted by self-interest, and think in utilitarian and calculating ways by weighing the risks and benefits of available options in order to best attain their goals (Good 1994; Young 1982; Hunt and Mattingly 1998). Rational thought is assumed to be “logical” in that it fulfills empiricist, positivist, and naturalist aspects of thought as derived from the Enlightenment (Gaines 1993). Normative theorists thus assume that behavior is predicable given that people make logical decisions. Moreover, rationality is assumed to be unbiased, unemotional, and acultural (Gaines 1993; Gordon 1988). The normative model is criticized for proposing how an individual, as the primary decision maker free from external constraints, *ought to* act, and for being bound to Western-cultural thought processes (Good 1994; Garro 1998).

Descriptive models of decision making and reasoning, by contrast, are focused on “discovering how decisions are actually made, [and] on understanding the reasoning process” (Garro 1998:324). Descriptive models are used primarily by anthropologists because they are culturally grounded. This research employs a descriptive model approach to understand patients’ and clinicians’ reasoning through the analysis of their choices of treatment for ESRD. This entails deconstructing the sociocultural components of treatment decisions, and, when relevant, interpreting decisions within a historical context and ethnic value system.

Anthropological and psychological studies show that people do not make choices and/or reason in ways predicted by normative theorists. For example, anthropologists have found that people make decisions in social groups rather than individually (Mathews 1987; Janzen 1978),

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al., 1982), hormone replacement therapy (Hunter, et al., 1997), neonatal intensive care (Levin 1990), psychiatric emergencies (Morgan 1990), and even noncompliance (Donovan and Blake 1992).

emotions (which are not universal) are integral to cognitive processes (Lutz 1988), and people use discrete tests instead of calculating probabilities to assess the risk of uncertain outcomes (Quinn 1978).

Psychologists have examined decision making largely through “prospect theory.” Prospect theory proposes that choices involving gains are often risk averse and choices involving losses are often risk taking (Tversky and Kahneman 1981; Kahneman and Tversky 1982). Psychologists have argued that when making choices, people do not perform consistent, coherent, or complex calculations of the utility of each alternative (Tversky and Kahneman 1981). Rather, they tend to use procedures that simplify the decision-making process (Moskowitz, et al., 1988; J. Young 1980). Decision making is often based on subjects’ past experiences, social context, incomplete information, and biased information processing (Moskowitz, et al., 1988; J. Young 1980; Rothman and Salovey 1997). Decisions thus rarely approximate scientific models of rationality (A. Young 1981; March 1994).

Anthropological studies of decision making are largely informed by an approach derived from cognitive anthropology to identify the cultural logic framing the choice of alternative (medical) services. Anthropologists have examined decision making in a wide range of nonmedical contexts.<sup>10</sup> Only about a dozen anthropologists have looked at patients’ decision making in medical contexts. Garro explains that “Decision making analyses attempt to understand what people do when faced with an illness and why. Thus, the focus is on the aspect of choice for health-related behavior” (1982:1451). Specifically, studies have investigated health seeking behavior, treatment choices, and other medical decisions.

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<sup>10</sup> See, for example, studies of farmers’ decisions regarding formal farming recommendations (Gladwin 1976); Mexicans’ decisions about the appointment of auxiliary personnel for religious festivals (Mathews 1987); and Mfantse decisions about selling fish at the market (Quinn 1978).

Medical decision-making studies are useful in that they can generate predictive models of health care decisions to understand health service utilization (Auerbach 1982). Most of these studies were conducted in pluralistic societies (those with multiple coexisting means of treating sickness) in the early 1980s (Auerbach 1982; Blue 1991; Early 1982; Hunt 1998; Mathews and Hill 1990; Sargent 1982; Weisberg 1982; J. Young 1980, Young and Garro 1981). Within the US, and other non-pluralistic societies, only a few studies have examined medical and treatment decision making by patients and clinicians (Keefe 1982; Scrimshaw and Souza 1982; Mattingly 1998; Kayser-Jones 1995; Hurwicz 1995).

One facet of decision-making theory is determining the goals which motivate peoples' choices because these goals will signal cultural concerns (Mathews 1987; Nardi 1983). In this dissertation research, I have used goal theory as a tool to elicit other culturally-relevant concerns informing patients' decisions that might not otherwise be expressed. This will help determine whether patients have goals they hope to achieve by obtaining a transplant or remaining on dialysis which guide their treatment choices. As I will discuss in Chapter 7, applying goal-theory to medical decision making has limits particularly among people with a chronic illness.

The way in which information is presented or "framed" is theorized to effect patients' decisions. Most studies of framing have been done in hypothetical situations and the empirical findings are inconsistent (Rothman and Salovey 1997). In medicine, framing studies seek to determine whether the presentation of clinical information influences patients' treatment decisions (Siminoff and Fetting 1989; O'Connor, et al., 1996; Fisher 1983). Clinicians can frame information in various ways. Most studies show that different presentations of probabilistic information on the risks and benefits of treatment effect patients' treatment choices, e.g., there is a 75% survival rate or a 25% chance of mortality (Hux and Naylor 1995;

Llewellyn-Thomas, et al., 1995; Jacoby, et al., 1993). Yet other studies show that framing can also occur by: a) presenting treatment options in a certain order (Fisher 1983); b) discussing some treatment options more enthusiastically than others (Perras, et al., 1984; Jacoby, et al., 1993); and c) using presentational and persuasional strategies to provide patients with the information necessary to make treatment decisions (Fisher 1983).

This dissertation study is informed by a decision-making framework drawn from behavioral sciences. This study intends not to create a decision tree model (e.g., Gladwin 1976) but rather to understand the process of decision making for treatment of ESRD, which itself should be predictive. The approach to decision making here assumed that a variety of decision-maker-specific characteristics affected treatment decision making. The research framework was based on the premise that decision making on the part of patients and clinicians was influenced and/or informed by social and cultural values and beliefs, and that appropriate understanding of decision making should therefore rest not only on biological and behavioral (e.g., medical) perspectives, but also on social (e.g., relational and personalistic) and cultural (e.g., epistemological and symbolic) viewpoints.

Using the framework set up by Siminoff (1987), this study addressed four questions to understand how sociocultural factors inform their responses: 1) what are the alternatives available to decision-makers; 2) what are the criteria decision-makers use to select among the alternatives (e.g., what factors are considered when making decisions); 3) what decision-maker characteristics alter the perception and evaluation of the alternatives; and 4) what is the decision-making process (e.g., how do people weigh the criteria).

### What are the alternatives available to decision-makers?

Previous research on decision making shows that there are often fewer subjectively available treatment alternatives than those which are formally available. Nephrologists face two decisions: whether or not to tell patients about available treatment options and whether or not to refer patients to the transplant center. Patients face several choices, the main one being whether to remain on dialysis or seek a transplant.<sup>11</sup> Those who chose to seek a transplant must decide whether to accept or ask for an offer of a living donor kidney. There is evidence that certain conditions alter the attractiveness of alternatives for people at different times because the advantages of an alternative are not entirely clear-cut so as to lead to an 'automatic' decision (Moskowitz, et al., 1988). In the case of patients seeking a transplant, the condition of having available living donors will be shown, in Chapter 8, not to automatically lead patients to obtain a transplant, as might be expected. Lastly, transplant professionals must decide what to do about marginal patients seeking a transplant. Their options are to: wait-list, not wait-list, put on hold, or reevaluate patients after further tests.

### What are the criteria decision-makers use in selecting among the alternatives?

Previous research has found that two kinds of criteria are generally operative (J. Young 1980; Llewellyn-Thomas, et al., 1984; McIntosh 1974). The first of these are termed invariant criteria which are decision-making factors that are perceived as given, non-elective features of the patient or the patient's disease, e.g., biomedical characteristics like blood type and demographic parameters, such as age. The second set of criteria, conditional criteria, are factors that are perceived as matters of preference or election. Traditionally included in this category are the personal, economic and social circumstances of patients, and training and organizational

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<sup>11</sup> The choice between different dialysis submodalities (e.g., hemodialysis and peritoneal dialysis) is not discussed in this study.

traditions of healthcare professionals, which may be brought into the decision-making process on an elective basis.<sup>12</sup>

Chapter 6 examines the factors influencing nephrologists' decisions to communicate treatment options to patients. There is a broad literature on information-giving by physicians.<sup>13</sup> Four types of information physicians may give patients pertain to: general medical information, drugs and treatment, procedures and examination, and illness (Hall, et al., 1988). Studies of information-giving seek to assess variation in the content and structure of communication exchanges (Street 1992a). These studies take one of two approaches: a) the 'individual differences' perspective, and b) the 'mutual influence perspective' (Street 1992a:1155).

The first approach examines variation in physicians' and patients' communication according to differences in their 'styles' of communicating. Such studies examine how differences in the way patients or physicians communicate are linked to their personal, social, and cultural backgrounds (Waitzkin 1985).

The second approach examines how physicians adapt their communication styles to patients and vice versa in response to the patient's sex, age, and ethnicity. Thus, three factors influence information exchange during the clinical encounter: characteristics of the doctor, patient, and clinical situation (Roter and Hall 1992; Waitzkin and Stoeckle 1987). Because these factors affect nephrologists' information-giving, which is examined in Chapter 6, it is important to review each one in greater detail below.

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<sup>12</sup> I do not necessarily agree that socioeconomic status is a factor that can fluidly change based on choice, as these words misleadingly imply.

<sup>13</sup> Much of this literature relates physician-patient communication to patients' outcomes (e.g., satisfaction with care, compliance with the medical regimen, information recall, and health improvement. See Hall, et al., 1988 for a review; Garrity and Lawson 1989).

## *Physicians*

The degree to which physicians communicate information to patients is based on several factors, including their demographic background, professional experience, need for power, and beliefs pertaining to information exchange (Waitzkin and Stoeckle 1987:350). Physicians' ideological orientations toward communication include: a) giving information piecemeal; b) withholding negative information to create a hopeful climate (e.g., Taylor 1988); and c) providing patients all information about their prognosis because they have a right to know (Mathews 1983; Waitzken and Stoeckle 1972). Studies show that physicians control the consultation process and patients accede to physicians' communicative dominance (Todd 1989; Street 1991).

Waitzken and Stoeckle (1972:187) contend that the need for power relates to physicians' practice of withholding information: "A physician's ability to preserve his own power over the patient in the doctor-patient relationship depends largely on his ability to control the patient's uncertainty." In other words, physicians have 'power' over patients by controlling the information they communicate to patients, keeping patients in a state of uncertainty, and thus maintaining patients' reliance on physicians (Waitzkin and Stoeckle 1987:346). Although Waitzken (1985:8) found no empirical support for this hypothesis, other studies found data indicating physicians' control of information exchange (see Clark, et al., 1991; Amir 1987).

A typical part of information-giving is giving patients directives to get a certain treatment (Street 1991; Todd 1989). Giving directives can be seen as physician involvement in patients' treatment decision making. Physicians' use of directives has been shown to be related to patients' "race," notably, physicians tend to give more directives to get a mammogram to "white" than to "black" women (Fox and Stein 1991).

Physicians tend to overestimate the amount of information they give patients and underestimate patients' desire for information (Waitzkin 1985). Despite evidence showing that physicians do not always provide patients enough information, the majority of people consulting a physician wish to find out as much as possible about their condition and prognosis regardless of social class (Beisecker and Beisecker 1990; Boreham and Gibson 1978; Waitzkin and Stoeckle 1972; Cartwright 1964; Ley and Spelman 1967). Studies show that physicians do not provide as much information as patients want because patients do not communicate their desire for it (Beisecker and Beisecker 1990; Boreham and Gibson 1978).

Physicians have been shown to underestimate patients' comprehension of medical terms and concepts (McKinley 1987). As a result of this misperception, physicians withhold information to simplify medical explanations. Since patients generally lack the medical expertise to interpret their clinical condition, they are left in a position of relying on physicians to initiate discussion and treatment. Thus physicians may perceive patients who wait for them to offer explanations as disinterested or unable to comprehend (McKinley 1987:299). These studies reveal that information-giving is an interactive process.

This study examines whether nephrologists engage in framing of the treatment options for ESRD and thus influence patients to select one treatment more than another. Doing so may constitute a factor in shaping patient's access to transplantation. Few studies have identified the possibility that nephrologists frame their educational discussions of renal replacement options in order to steer patients to one therapy or another (Campbell 1991; Kosky 1990). One study showed that a dialysis program increased its peritoneal dialysis population from 0% to 85% over five years because the staff exhibited greater enthusiasm towards peritoneal dialysis than other



forms of dialysis (Perras, et al., 1984). Chapter 6 examines whether nephrologists engage in different forms of framing their discussion of treatment options for ESRD.

### *Patients*

Patient factors may also influence the process of information exchange during the clinical encounter (Roter and Hall 1992). Physicians tend to give varying amounts of information in response to patients' class, ethnicity, education, income, sex, and age (Waitzkin 1985). Sociolinguistic research has shown that physicians communicate fewer medical explanations to and spend less time in a consultation with patients of lower "social class," and poor and minority patients (Pendleton and Bochner 1980; Pendleton 1983:46; Mathews 1983; Hall, et al., 1988). Conversely, more educated patients tend to be more expressive, and expressive patients receive more diagnostic information (Street 1991). In fact, patients who ask more questions receive more information from physicians (Street 1991; Amir 1987; Boreham and Gibson 1978; Greenfield, et al., 1985). The relationship between class and communication is explained well by Waitzkin in the following way: "working-class patients tend to take little initiative in questioning and directing doctors' attention to matters of concern, including sources of suffering and social context" and "working-class patients are also less likely than middle-class clients to express verbal disagreement with physicians who hold a higher class position" (Waitzkin 1991:24). Moreover, working-class patients tend to not speak as analytically as physicians and rely on nonverbal communication to express themselves (Waitzkin and Stoeckle 1972:194). Consequently, physicians tend to view working-class patients as less interested in receiving information about their medical problems (Pendleton and Bochner 1980), and as incompetent in understanding information because of linguistic differences (Waitzkin and Stoeckle 1972:195).

With regard to ethnicity, gender, and age, physicians have been found to present more information to “whites” than “blacks” or “Hispanics” (Hall, et al., 1988; Roter, et al., 1988). Studies show that physicians give more information to female than male patients (Hall, et al., 1988; Roter, et al., 1991). Studies also show that physicians give less information and less consultation time to older patients than to younger patients (Haug 1996; Clark, et al., 1991).

### *Clinical Situation*

Situational characteristics of the clinical encounter may influence the manner in which physicians’ give information (Waitzkin 1985; Goss 1981; Roter, et al., 1988). Situational characteristics include: a) the clinical setting, e.g., in a private office, in an outpatient clinic, or in a hospital; b) the length of acquaintance between doctors and patients; c) physicians’ clinical load; and d) the types of patients in the physicians’ practice, e.g., chronically vs. acutely ill patients.

Waitzkin (1985) found that internists spend less time giving information to patients when they had a busy clinical load, and that doctors earn more money when they saw more patients, hence the incentive to have a busy schedule. Patients can be discouraged from asking for information because of fear of receiving negative responses from an already overworked staff (Mathews 1983). Internists also provide patients more information when they know patients longer, and when doctors see a higher proportion of chronically ill patients (Waitzkin 1985). In a review of 61 studies, Roter, et al., (1988) found that physicians give more partnership statements and spend more time with clinic patients than with private patients.

### What decision-maker characteristics alter the perception and evaluation of alternatives?

This aspect of decision making will only be examined for patients included in this study. Chapter 7 determines the extent to which patients' sociodemographic, economic, and clinical variables account for the variance in their treatment decisions.

### What is the decision-making process?

The decision-making process involves weighing and sorting through each of the invariant and conditional criteria used to select a given alternative. The decision-making process is proposed in this dissertation to be largely cultural in nature because different values and beliefs are likely to influence the importance placed on the selected criteria. Chapters 6 through 10 examine the principles whereby information was used and organized by clinicians and patients to reach final decisions. Before addressing how clinicians and patients make treatment decisions, there is additional background information to present that helps contextualize the themes and issues shaping the decision-making criteria and process. The following chapter discusses in detail the methods and research design used to conduct this study.

## **CHAPTER 2: RESEARCH DESIGN AND METHODS**

This chapter presents the research design and methods used to conduct this anthropological research as well as the methods of data management and analysis. It begins by portraying the research setting and then moves on to describe subject selection, research methods, and methods of data analysis.

### **Setting**

Fieldwork was conducted in a midwestern, metropolitan city, Cleveland, Ohio whose metropolitan area is home to about 2,000,000 people. The population is ethnically heterogeneous. Sixteen percent of the greater metropolitan area is African American, and there are many other distinct ethnic groups from the Caribbean and Europe, especially Eastern Europe (Van Tassel and Grabowki 1996). The city itself (population: 500,000) is 46% African American. The population in Ohio in 1996 was 11,462,720. According to 1990 Census Update, the state population divided by “race” was 88% “white” and 10.5% “black” (Renal Network, Inc. 1997). Fieldwork was conducted over a period of 18 months, from April 1997 to October 1998.

This study was conducted in six different research sites, all located within greater Cleveland. One field site was American Hospital (AH), a major teaching hospital affiliated with a medical school and a university, located in the inner city area of Cleveland. This hospital was the overall context for various other field sites: a) the dialysis unit for medically unstable patients; b) the nephrology clinics where patients met with nephrologists; c) the transplant clinics where patients who wanted a transplant met with transplant surgeons and nephrologists; d) the transplant center where patients interested in transplantation met with transplant social workers and nurses; and e) the kidney-pancreas selection meetings where transplant professionals decided on marginal cases.

Fieldwork was also conducted at five free-standing satellite dialysis centers affiliated with American Hospital, also known as Neighborhood Dialysis Center (NDC), and one free-standing dialysis center affiliated with another teaching hospital, City Hospital (CH). The NDCs were selected as research sites because all AH patients attend them which allowed for a case study of AH patients and their nephrologists. The clinical sites and the roles of dialysis and transplant professionals are described in further detail in Chapter 5.

In 1996 there were a total of 8,240 patients with end-stage renal disease (ESRD) in Ohio. The number of in-center patients in 1996 was 6,623 (80.4%) (Renal Network, Inc. 1997). Based on a slightly lower count of 7,977 ESRD patients in Ohio in 1996, the ethnic breakdown was 57.6% European-American and 40.25% African American (Renal Network, Inc. 1997). There were 86 dialysis facilities in Ohio as of 1995 (HCFA 1997). In 1995, the average percent of African American patients was 52.6% at all dialysis units in Ohio. In 1995, the population of Cuyahoga County was 1,398,169 (The Renal Network, Inc. 1997). At that time, the incidence of ESRD was 402 per million population (pmp) and the prevalence of ESRD was 1,212 pmp (ibid.).

The study sample comprised 1.2% of in-center dialysis patients in Ohio and 4.7% of all dialysis patients in Cuyahoga County (n=1,694). In 1996, 100 renal patients became end-stage and began dialysis at AH, though not all were eligible for a transplant. The African American patient population of AH as a whole was 33%. The ethnic composition of patients in the study sample closely matched their composition in Ohio in 1996. Dialysis centers in this study varied in patients' ethnic composition, reflecting the constituency of the dialysis center's locale. For instance, NDC 1 represented the population of the inner-city, being predominantly African American, while NDC 3, located in the suburbs and furthest from AH was primarily

European-American. This research is primarily based on interviews and data collected from a random sample of 79 dialysis patients eligible for a transplant.

### **Mechanism of Subject Contact**

All eligible patients were approached in person while they were on dialysis. I introduced myself as a student at the local university and explained the nature of this research. Prior to obtaining consent, I informed patients that participation in this study is confidential and guaranteed their anonymity. To obtain informed consent among the AH patients, I presented patients with the consent form, let them read it (or I read it to them if they could not read) and then reviewed it with them ensuring their comprehension, and then they signed the bottom of the form. Patients who could not sign because of the graft<sup>14</sup> in their arm, were asked to sign ‘x’ under the observation of a technician or nurse, who then signed their own name as a witness. If patients so desired, they were given a photocopy of the consent form.

CH patients provided verbal consent (and were given an information sheet). The informed consent process was changed because it became apparent that the written consent form, used with AH patients earlier in the study, had provided more than enough information, and many patients had difficulty with their vision due to comorbidities. Further, several patients were leery of signing a form, even after having read its contents. Thus it became apparent that informed consent easily could have been conducted verbally. With hindsight, informed consent through verbal, rather than written, communication was an easier process because it more actively engaged the researcher and the subject in discussion.

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<sup>14</sup> The graft, also known as the “access,” is the site where needles are inserted into a patient to retrieve and return blood for cleansing. The arm should not be moved for fear of disturbing blood flow. The access will be described in greater detail in Chapter 3.

## **Sample Selection**

### **Dialysis patients**

Patients with end-stage renal disease were eligible for participation in this study if they: 1) were 18 years of age or older; 2) were patients of AH nephrologists; 3) were eligible for a transplant as determined by their nephrologists and as indicated in patients' medical charts; 4) had no prior transplant; and 5) were competent and able to act as decision makers. Competency was determined by the extent to which patients were knowledgeable and consistent about their own medical history and treatment decisions by asking them the first few questions of the interview. Patients who were not competent were not included in the study sample.

As many patients as possible were recruited during a three-month recruitment period. Patients were approached at least three times. Priority of patient selection was made in order of the least number of years on dialysis to obtain a more recent recall of treatment education and decision making in patients' illness careers. Patients were selected within this system according to the timing of their dialysis shift in the course of the day shift. The list of patients was organized by time of day so that patients were selected in chronological order within the list. In addition, as days alternated, so too did the selection of patients down the list. This is because patients' dialysis was scheduled according to one of two weekly schedules: Monday, Wednesday, Friday or Tuesday, Thursday, Saturday. Therefore, selection of patients was conducted within these two different (weekly) schedules. A large portion of the patients were patients of AH nephrologists. This sampling method allowed for a case study of AH patients.

There were 35 eligible patients who were not interviewed. The reasons for not interviewing these patients are listed in Table 2.1. Eleven patients were not approached because

the sample quota had mistakenly been reached and the time limit for initial data collection ended. Three female patients were found to be incompetent and thus ineligible for participation.

**Table 2.1 Gender breakdown and reasons for not including eligible patients**

Reasons	Gender		Total
	Male	Female	
Died	1	1	2
Received a Transplant	2	0	2
Never Approached	4	7	11
Sick/Sleeping	3	9	12
Refused	7	1	8
Total	17	18	35

A subsample of patients was recruited at another hospital, CH, in order to recruit more European-American patients into the study, despite the criterion for patients to be of a AH nephrologist. This occurred after completing interviews with all AH eligible patients. AH had relatively few European-American patients, perhaps owing to its inner-city location. City Hospital was selected because it is located in a part of Cleveland with a large European-American population.

Because this study sought to explain the low rate of kidney transplantation among African Americans as a matter of ethnic identity, and not biology, it was essential to identify the ethnic identity of recruited patients to facilitate comparison between those who chose to remain on dialysis and those who desired transplantation. To identify ethnic identity, patients were asked to self-identify their ethnic affiliation or heritage. The benefit of this approach is that it avoids the potentially erroneous classification system used by the research investigator. The potential drawback of this approach is that respondents, as members of American culture, may have identified their ethnic affiliation in a way that replicates American notions of “racial” classification.



Two main types of patients were recruited into the study: those who chose to remain on dialysis (who will be referred to as “con-transplant” patients) and a control group of those who desired transplantation (who will be referred to as “pro-transplant” patients). Patients in the former group include both those who were undecided and those who refused to seek a transplant. Undecided patients were grouped as con-transplant because they did not want a transplant at that time. There were no significant sociodemographic and economic differences between the undecided and refused patients. The latter group was composed of patients who desired a transplant including those who were interested in a transplant (but may not have begun transplant evaluation), those who had begun the process of transplant evaluation, and those who were active on the transplant waiting list.

It is important to recognize that patients’ decisions are not always definitive. As is discussed in Chapter 8, patients change their minds frequently. In addition, patients may make the effort to seek a transplant but may be somewhat unsure of their decision. Similarly, patients may be temporarily uncertain about a transplant until they begin to feel in better health. For the purposes of analysis, patients are classified according to their current decision.

However, there are two reasons that support its use. First, dichotomizing the choices of patients is useful for the purposes of answering one research question, namely, what sociocultural beliefs and values inform patients’ decisions to not seek a kidney transplant, compared to those who do want one. As will be discussed at greater length in Chapter 4, comparing the first four of these groups would not yield greater insight into the research question because I am interested in their decisions, not actions *per se*; some patients had made decisions without yet acting upon them. Dichotomizing patients thus allowed me to examine the shared sociocultural beliefs and values that contributed to their disinclination to seek a transplant.

Second, nephrologists' and dialysis staff's interactions with their patients reinforced a dichotomous perception of patients' treatment choices. Specifically, they are legally required to ask patients on a routine basis whether they would like to obtain a transplant. The investigator's question to patients in this study, "Are you interested in getting a transplant?" does not force the patient to think in new ways; rather, this is a commonly asked question in the ESRD environment. Dichotomizing patients was therefore implemented as a functional approach to examine the research question.

### Healthcare professionals

A variety of dialysis and/or transplant healthcare professionals at AH informally and formally participated in this study. These included the following categories of professionals: nephrologists, transplant nephrologists, transplant surgeons, transplant coordinators (nurses), dialysis nurses, dialysis technicians, transplant and dialysis social workers, and the transplant medical secretary. To gain a broader sense of the psychosocial and medical concerns of dialysis patients, I interviewed dialysis social workers from each of the dialysis centers. I also formally interviewed six dialysis and transplant professionals from Cleveland Medical Center (CMC), a competing transplant center for comparison. Two nephrologists from two AH-affiliated NDCs were also formally interviewed. Dialysis technicians and nurses were also informally consulted. See Table 2.2 for the number of dialysis and transplant healthcare professionals formally interviewed in this study.

**Table 2.2      Dialysis and transplant healthcare professionals formally interviewed**

Healthcare Professionals	N
Nephrologists <sup>1</sup>	12
Transplant Surgeons	2
Transplant Coordinators	4
Social Workers <sup>2</sup>	11
<u>Total</u>	<u>29</u>

1. Includes both nephrologists and transplant nephrologists.

2. Includes both dialysis and transplant social workers.

### **Methodology**

This anthropological study used various ethnographic methods and techniques, including in-depth interviews, informal discussions, participant observation, and medical chart reviews to obtain qualitative and quantitative data. Field data were supplemented by reviewing written pamphlets, organizational statements, and relevant literature in the fields of anthropology, nephrology, and transplantation.

#### **In-depth, open-ended, directed semi-structured interviews**

In-depth interviews were conducted with dialysis patients and dialysis and transplant healthcare professionals. Each type of patient (pro-transplantation or con-transplantation) and each type of healthcare professional was asked a core set of questions unique to that group of subjects. The lists of questions used for the in-depth interviews are available in Appendices I-IV.

#### ***Patient interviews***

In order to become familiar with dialysis, living with ESRD, and the nature and timing of treatment decisions, pilot interviews were conducted with a group of AH dialysis patients (n=30; 24 with patients in this study, 6 with re-transplant patients). ESRD patients were interviewed three times (once every three months) to track their treatment decision-making process, see Table 2.3. Interviews were conducted over a six month period of time to determine the stability of

treatment decisions. These interviews sought to explain how cultural, religious, economic, and other factors influenced patients either to remain on dialysis or seek a transplant specifically, and how these factors affect access to kidney transplantation in general.

Topics covered in the initial patient interview included: medical history, education about treatment options for kidney disease, decision-making preferences of their physicians, treatment preferences and perceptions of influences on those choices, the availability and desirability of living (related) donors, and sociodemographic variables. Topics covered in the follow up interviews included whether a change in treatment preference occurred, the reasons for the change, and the actions taken upon these decisions. At the six month mark, all AH patients were telephoned to screen for changes in treatment choices. Patients who had received a transplant by the time of their first or second follow-up interview were not re-interviewed (n=1).

**Table 2.3 Patients interviewed at each stage of the study**

Gender	Interview #1	Interview #2	Interview #3
Female	40	40	38 <sup>1</sup>
Male	39	39	37 <sup>2</sup>
Total	79	79	75

1. Two women died (Rosa, June).

2. One patient received a transplant (Ben), and one refused to be interviewed (Lewis).

In the first interview, all patients were asked to rate, on a scale from 1 to 5, their perception of how encouraging their nephrologist was for them to seek a transplant. After providing a number, they were asked to explain what their doctor said that was encouraging to them.

During the first and second interviews, con-transplant patients were initially asked the open-ended question of why they did not want a transplant. Patients were subsequently asked to complete a card sort (or pile sort).<sup>15</sup> The card sort was conducted to map the cognitively defined

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<sup>15</sup> The idea for doing the card sort derived from the work by J. Young (1980, 1981).

reasons and test for intracultural variation (Bernard 1988:234). Rank ordering is a way to produce powerful interval level data (Bernard 1988:237). I had prepared a set of index cards, each with a reason for not wanting a transplant written on it, based on the semi-structured pilot interviews and the medical decision-making literature. These reasons included: 1) I am doing OK on dialysis; 2) I do not want to be “cut on”; 3) I know people who had unsuccessful transplants; 4) I am afraid of being worse off from a transplant; 5) I am afraid of taking transplant medications (the side-effects); 6) I am afraid of the costs of medications; 7) I am afraid of a foreign part in my body; 8) I am afraid for religious reasons; 9) I am afraid of death; 10) I do not want to go through all the tests to get on the transplant waiting list; 11) I am concerned about not getting a kidney from a donor of my ethnic/racial background; and 12) I do not want to return to work.

Several more reasons were added to the pack (based on responses from the first interview) at the second card sort. The newly added reasons included: 13) I am too old to get a transplant; 14) I do not want to go through the disappointment of a transplant not working; and 15) I have kids and need to take care of them. Patients were given the set of index cards and asked to select the most relevant cards. Afterwards, patients were asked to put into rank order the cards they had selected. The last step involved asking patients to explain why they chose each card.

To supplement the interviews, data were collected, with the patient’s permission, from the patient’s medical record, including: age, ethnicity, marital status, length of time with ESRD, etiology of renal failure, transplant status (e.g., active, in process, undecided, refused), potential medical and psychosocial contraindications to transplantation (e.g., need to lose weight, wait for Lupus flare to die down), address, telephone number, and insurance providers.

### *Dialysis and/or transplant professional interview*

Nephrologists were interviewed about the factors influencing the timing and order of the presentation of ESRD treatment options, factors preventing them from referring patients, medical and psychosocial criteria they use to evaluate patients for transplant, and their demographics. Nephrologists (n=4) of the AH patients (n=61) were informally re-interviewed about their perceptions of their patients' mental status, rapport with them, and medical/psychosocial suitability for a transplant. For each patient, the nephrologist was asked to rate on a scale from one to five, five being the highest or best, the nephrologist's perception of the patient's suitability as a transplant candidate. Afterwards, nephrologists were asked why they gave the patient that score.

Transplant surgeons, coordinators, and social workers were interviewed about the medical and psychosocial criteria they use to evaluate patients for transplantation, how they determine a patient's compliance and its import for transplant suitability, their perceptions of gender, age, and ethnic patterns regarding patients' decisions to turn down offered kidneys, remove themselves from the transplant waiting list, and accept living donor offers, and their demographics.

Dialysis social workers were formally interviewed about their perceptions of the factors preventing dialysis patients from wanting a transplant and accepting a living donor offer, and of gender, age, and ethnic patterns in patients' treatment decisions.

### Direct observation

Direct observation was conducted to perceive the (dialysis and transplant) sphere as my respondents saw it (Spradley 1979). Because much of people's knowledge is tacit, people are unable to verbalize in an interview details about a given matter. Therefore, observing people's

interactions and communication enabled me to obtain data that interviews could not provide. In addition, while the interviews provide data that tend to represent what healthcare professionals do in an ideal situation, direct observations of what they actually do offer a glimpse into the ‘real world’ of clinical practice. The distinction between ‘scientific’ theory used by healthcare professionals and their actual, medical day-to-day practice has been a helpful tool in identifying clinicians’ explanatory models, that in part, influence the diagnosis and form of treatment offered (Kleinman 1980:110; Helman 1985:294).

I observed six different clinical situations: 1) pre-dialysis education classes to educate patients whose renal disease was close to becoming end-stage (n=2); 2) long-term care plan (LTCP) meetings in which the dialysis staff reviewed each dialysis patients’ treatment modalities, medications, and psychosocial evaluations (n=7); 3) nephrologist-patient clinics (n=12 total clinic days), and surgeon-patient clinics (n=2 clinic days); 4) transplant coordinator and social worker meetings with patients interested in transplantation (n=4); 5) kidney-pancreas selection meetings which evaluated potential kidney transplant recipients (n=15); and 6) annual review meetings in which transplant professionals update wait-listed patients on transplant-related issues (n=2). All occasions for observing clinical situations were randomly selected.

I attended only two pre-dialysis education classes because their format and content was virtually identical. These highly-structured meetings demonstrated how clinicians present treatment options and respond to patients’ questions, and the extent to which dialysis nurses and social workers systematically and formally educate patients about their treatment options.

I attended LTCP meetings (6 at AH and 1 at NDC 1) to identify how dialysis staff made decisions about patients' eligibility and referral for transplantation. These meetings offered the opportunity to see how sociocultural values wove their way into the staff's decision making.<sup>16</sup>

I observed nephrologist-patient clinics among five different nephrologists. Since five of six nephrologists held patient clinics, I had to choose who to shadow each day. Generally, I had a nephrologist in mind who I wanted to shadow, depending on the previous number of times shadowed. When I arrived at the clinic I reviewed each doctor's patient schedule (posted in the back hallway) to assess how many patients they were to see that day. The greater the number of patients, the more interested I was in shadowing the physician because of the increased likelihood of observing the education process. But the scheduled number of patients often changed at the last minute because some patients canceled their appointments or failed to show up.<sup>17</sup> I also reviewed the schedule to see who the patients were. I wanted to shadow nephrologists who were to see patients who I had planned on interviewing but had not yet reached, or who I had already interviewed but wanted to see how they interacted with the doctor and to gain a sense of the doctor's perspective on that patient. While the transplant nephrologists followed a large number of patients who have had a kidney transplant, I concentrated my time with the dialysis nephrologists who followed dialysis patients pre-dialysis and after dialysis initiation.

The kind and number of patients nephrologists followed differed according to the time of the week or time of day. For instance, Dr. Julian, a transplant nephrologist, saw his dialysis

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<sup>16</sup> While attending additional meetings at the NDCs would have likely provided a greater base for comparison, the content and/or structure of the meetings was not a central feature of this research.

<sup>17</sup> According to Dr. Olson, "young black males" tend not to show up for their appointments, and there is a 50% chance that patients under the age 30 will not keep their clinic appointments.



patients on Monday mornings and his transplant (or post-transplant) patients on Monday afternoons. In addition, dialysis nephrologists saw most of their patients in the afternoon. Thus, I usually observed the clinic encounters in the afternoons, though observed a few that took place in the morning.

The nature of the timing of ESRD onset (see Chapter 3) meant that observations of the educational process could take place only with patients whose ESRD onset was progressive since there was no way to predict when to be present in the emergency room to observe initial interactions between nephrologists and new ESRD patients. Thus the analysis of how nephrologists communicate with patients about their treatment options in Chapter 6 refers primarily to patients with progressive onset of ESRD, unless otherwise specified. Because nephrologists educate patients in a process, methodologically, it was difficult to pinpoint exact days when patients would be educated about their treatment options and arrange in advance dates to observe this occurrence. In addition, the process-based manner of education meant that it was unfeasible to observe the entire range of discussions about treatment options in which nephrologists engage with their patients over time.

I attended almost every kidney-pancreas selection meeting from February 1997 to September 1998.<sup>18</sup> The number of patients reviewed at each meeting ranged from approximately five to fifteen. I attended these meetings in order to learn what ethical issues the transplant team faces in their deliberations over wait-listing patients who are marginally suitable for transplantation. Observing how the team worked through their ethical issues revealed their cultural values and what they considered important criteria for wait-listing (or not) patients.

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<sup>18</sup> Four meetings were canceled because the surgeons were operating or were out of town. One meeting was missed due to the research investigator having influenza.

An innovative way of augmenting my understanding of the world of ESRD patients was through observing and interacting in two moderated Listserv discussion groups: dialysis@wugate.wustl.edu and trnsplnt@wuvmd.wustl.edu. The participants in the first group included primarily hemodialysis and peritoneal dialysis patients, and occasionally, a nephrologist, a transplant surgeon, a transplant coordinator, and a social worker. Many of the patients had previously undergone or were preparing to undergo a kidney transplantation. The second group consisted of transplant patients and professionals. There were approximately 270 and 375 non-concealed subscribers of each group, respectively. The kinds of discussions or “threads” that occurred (without my prompting) ranged from pros and cons of transplantation versus dialysis; patients’ experiences with different forms of dialysis and transplantation; questions and advice on coping with physical problems of neuropathy: restless leg syndrome, itching, numbness in extremities, inability to sleep at night; ethics of arriving late for dialysis, multiple listing, and foreigners receiving American kidneys; patient-dialysis staff relationships and power struggles; jokes about the inability to urinate, etc.

Permission to ask research questions on these groups was obtained from the group moderators. This method was efficient because a question could be posed to many people at once. The only drawback was that participants were self-selected (they all had access to a computer). Data from the Listserv groups provided contextual data about end-stage renal disease. In addition, I posed several questions to the group that had been asked of the study sample to enrich my understanding of the diversity of patients’ experiences. Some of these data are presented in the following chapter to supplement the findings from the study sample.

Multiple strategies were used to enhance the validity of the research findings. The strategies employed in this research included: a) triangulation, a form of replication which

involves using multiple data sources and research methods to obtain overlapping data (Crano 1981); b) thick description, a way of depicting phenomena using rich detail (Geertz 1984); c) self-reflexivity, a way of assessing one's own biases through awareness of her own subjectivity and its potential influence on perceptions of phenomena, since the investigator is a research tool (Scholte 1970); d) member checking, a way of asking informants different but related questions to ensure validity of the reply through consistency. This also involves verification by informants that the investigator's observations are accurate, and; e) maintaining a detailed and accurate paper trail to track the progression of ideas and inquiries. These research strategies strengthen the consistency and coherence of findings (Pelto and Pelto 1991:34).

### **Data Management**

A database and tracking system was used to manage the flow of data. Separate tables for tracking patients and healthcare professionals were constructed using SPSS for Windows 95. Patient and healthcare professionals were assigned unique identifiers for tracking and data analysis purposes. All interview data and field notes were transcribed verbatim and entered into the word processing computer program, Lotus Word Pro 3.0.

### **Data Coding**

Patient and the healthcare professional interviews yielded an extensive amount of qualitative and quantitative data. The interview instruments were based on a triangulated approach to data collection whereby different techniques were used to collect the data. The interview instrument relied on three types of data: wholly open-ended questioning, directed semi-structured questions, and scaled responses. Qualitative data from nominal variables were coded in an iterative process, in which codes were developed from the pilot interviews. Codes were altered, deleted, or added upon further data collection and preliminary analysis, whereupon

the coding sheet was updated. A coding rule book was developed to provide definitions and rules for each code and a set of examples for each (Spradley 1979). After all interviews were coded, they were rechecked to verify their codes. This ensured the comparability among subsequent interviews.

### **Data Analysis**

As an exploratory study, this investigation presents the range of factors influencing dialysis patients' and healthcare professionals' treatment decisions because: a) this information has been, as yet, currently unknown, and b) all patient and healthcare professional perspectives should be represented in this dissertation. This study could have taken another route to data analysis and write-up, used more often by other types of cultural anthropologists, by examining in even greater depth only a select few key treatment decisions through case analyses. The approach taken here, however, is consistent with the tradition of Medical Anthropology in writing for both anthropology and public health audiences by using both qualitative and quantitative data analyses. In addition, multiple quotations from respondents are presented in the following chapters in keeping with a postmodern emphasis on allowing the reader to interpret polyphonous perspectives on various phenomena (Clifford 1988).

As previously noted, this study examines how cultural beliefs and values inform treatment decision making. In other words, culture informs how people think about a problem and decide which options to choose to resolve it. But what does 'inform' really mean? Here I explain the term 'inform' in relation to culture, knowledge, and cognitive processes. To do so, I draw upon the work by linguistic and cognitive anthropologists, respectively, Edward Sapir and Richard Shweder.

The first proposition that advances our understanding of “inform” is that knowledge is fundamentally cultural. Edward Sapir’s conception of the interrelationship between language and culture is expressed in the following:

“[The forms of each language] establish a definite relational feeling or attitude towards all possible contents of expression and, through them, towards all possible contents of experience, in so far, of course, as experience is capable of expression in linguistic terms” (1924 in Mandelbaum 1985:153).

In its strong form, the Sapir-Whorf hypothesis proposes that speech constitutes thoughts about reality, and that those thoughts reinforce cultural knowledge.

Given this relationship between language and culture we can draw upon Shweder’s notion of “intentional worlds” to clarify the meaning of the word “inform.” Intentional worlds are sociocultural environments constituted of “human artifactual worlds populated with products of our own design;” such “intentional things have no ‘natural’ reality or identity separate from human understandings and activities” (Shweder 1990:1). The principle of intentional worlds is that humans create their environment, or their culture, and thus affect it. Conversely, the existence of objects or thoughts -- the fact that they are/were intentionally produced (consciously or unconsciously) -- has an affect on humans who live in the sociocultural environments in which they and the objects inhabit. In other words, both humans and those things within sociocultural environments “interpenetrate each other’s identity” (Shweder 1990:1). Every aspect of culture is interrelated (and interdefined, that is, each variable aids in defining or giving meaning to another) and cannot be defined alone. “What makes their existence intentional is that such things would not exist independent of our involvements with them and reactions to them; they exercise their influence in our lives because of our conceptions of them” (Shweder 1990:2). We can learn “culture” by accessing any domain of intentional worlds, and through the medium of language.

What we say is cultural. Our words are created by us, and yet they exert their influence upon us -- upon our thinking.

As a study contributing to cross-cultural bioethics, some of the data are analyzed using bioethical constructs (see Chapter 10). While I seek to show the cultural bases of bioethical constructs and their actual applications and/or manifestations by healthcare professionals, using them here facilitates a comparative approach to the cross-cultural study of healthcare allocation.

Descriptive analyses were conducted to provide a detailed description of patients' decision-making process in the context of their illness career and of their clinician encounters. All interview data and field notes were analyzed for content. Content analysis is an established qualitative method by which written data is analyzed for themes relevant to the topic of study (Bernard 1988). It is useful for gaining insight into why people say what they do and the effects they intend (Babbie 1992).

Content analysis of transcribed interviews and records of participant observation involved counting and coding of social and cultural themes, values, symbols, patterns, and repetitions (Pelto and Pelto 1991; Spradley 1979) that, in this study, indicated particular perceptions about patients, their suitability for kidney transplantation, and patients' own assessments of their decisions.

Coding entailed the categorization and indexing of patterns, concepts, and associations emerging from the data. Data analysis was thus not linear but an iterative process. During the ongoing analysis, assumptions derived from the study of initial cases were tested on later interviewees. Follow-up interviews with patients assessed the validity of the analysis of the patients' initial interview and helped to glean additional information to answer questions raised in the iterative process. Coded themes were linked to gain an understanding of healthcare

professionals' concepts of medical and psychosocial criteria, categories of social identity, and how these relate to perceptions of patient suitability for transplantation.

Patients' socioeconomic status (SES) was calculated according to Hollingshead's Two-Factor Index of Social Position (Hollingshead and Redlich 1958 in Miller 1991:351). This index (of five SES levels) is composed of an occupational scale and an educational scale. This index was selected because it did not rely on income in its calculations. Since many dialysis are physically unable to work, it would be unfair to rely on income as a helpful indicator of social standing. Because the occupation group "student" was not originally included in the classification scheme, I slightly modified the index to account for the three students in my sample. Students were rated according to the occupation they were training for, but then their occupational rank was demoted a level since they had not yet completed their training (e.g., Economist = Level 1, but a student studying to be an Economist was classified as Level 2). In addition, due to the maturity of the index, the category "computer programmer" was absent. I ranked this position as a Level 2 given my personal knowledge<sup>19</sup> of the training requirements and income levels associated with this and related occupations. Hollingshead and Redlich (1958 in Miller 1991:352) report a correlation between judged class with education and occupation as  $R_{1(23)} = .906$ .

Descriptive statistics and bivariate analyses were generated using SPSS for Windows 95 (Chicago, IL). Frequency distributions were produced for all variables. The standard two-sample t-test (or the Mann-Whitney U test for non-normal distributions, e.g., years on dialysis) was used to test differences between means (e.g., education, income). Nonparametric correlations using Spearman's rho were also used to test differences between means with ordinal

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<sup>19</sup> My husband is a Director of Information Systems.

variables of non-normal distributions (e.g., patients' ratings of nephrologists' encouragement). Differences in proportions were tested using Pearson's Chi-square test or Fisher's exact test if expected frequencies were less than 5. Pearson's partial correlations were performed to control for potentially confounding variables. All tests were two-tailed.  $P < 0.05$  was considered statistically significant. Statistical analyses of patients' treatment decisions were based on the decisions reported at the first interview.

Before we can examine patients' treatment decisions, it is imperative to understand the clinically defining aspects of end-stage renal disease, the advantages and disadvantages of treatments for it, and the institutional organization of dialysis and transplantation in the United States today. The next chapter provides an overview of the clinical and organizational aspects of end-stage renal disease, dialysis, and kidney transplantation.



### **CHAPTER 3: CLINICAL, HISTORICAL, AND ORGANIZATIONAL OVERVIEW OF DIALYSIS AND TRANSPLANTATION**

Before examining the problems with access to transplantation and how patients and clinicians make treatment decisions, it is necessary to understand the clinical aspects of kidney disease and the nature of the treatment options themselves. This chapter presents a wide array of information about the clinical, organizational, historical aspects of kidney disease and its treatments as context for understanding subsequent chapters.

This material is covered in seven parts. The first part describes the clinical characteristics of end-stage renal disease. The second part reviews the treatment options available to patients. The following section presents population and survival statistics for each treatment option. The fourth section describes the forms of financial coverage for ESRD. The next two sections focus on the history and organization of dialysis and transplantation, respectively. The last part depicts the ethos of transplantation today.

#### **Clinical Characteristics of ESRD**

Most people are born with two kidneys. In adults, kidneys are about as big as a fist and weigh about five or six ounces. The kidneys have several major functions in the body, these include: 1) cleaning the blood by filtering out extra water, salt, and wastes; 2) making hormones that keep bones strong and blood healthy; 3) controlling blood pressure; and 4) maintaining a proper metabolic balance (Vander 1985). End-stage renal disease or chronic renal failure is permanent, kidneys failure (Sehgal 1999).

The main causes of ESRD are diabetes (one third of patients), hypertension (one fourth of patients), and other causes are glomerulonephritis and polycystic kidney disease (USRDS 1998). Much research is devoted to understanding the causes of kidney failure. However, the status of

knowledge of kidney failure is considered to be in the 'dark ages,' approximately 20 years behind cardiovascular disease (Kusek 1997). With chronic renal failure, wastes build up in the blood which must be removed by renal replacement therapy. Once the kidneys stop working, they usually do not work again (Tri-State Renal Network 1996). Kidney failure is known as a "silent killer" because there are no painful symptoms that forewarn patients of its onset, except fatigue, dizziness, and nausea.

Without forewarning, how do patients then realize that they have ESRD? Several factors influence the diagnostic process: a) the patient's clinical background; b) other patient factors; and c) the primary care provider's (PCP) willingness to refer. Clinically, kidney disease is characterized by two distinct patterns. One-third of new ESRD patients have progressive disease usually associated with heritable diseases such as polycystic kidney disease, diabetes, and hypertension (Ratcliffe, et al., 1984). These patients are aware that their kidneys are getting progressively worse. Many of these patients are referred by their PCP to a nephrologist early because the disease causing their kidney failure runs in the family and has a predictable prognosis. Such patients are therefore likely to receive medical attention before their kidney disease becomes end-stage (Ratcliffe, et al., 1984). In contrast, two-thirds of all new ESRD patients have chronic renal diseases with an unpredictable, emergent onset (Ratcliffe, et al., 1984). Since diagnosis of their renal disease is often delayed, such patients usually learn of their renal failure within days or weeks by requiring emergency care.

Second, other patient factors influence the diagnostic process. One study found that the major factor influencing the late pattern of referral (less than 1 month before ESRD onset) was the attitude of patients (Jungers, et al., 1993). Patients referred late were either aware of their renal disease and oncoming renal failure but were never advised by their PCP to consult a

nephrologist, or they had been evaluated by a nephrologist but discontinued follow-up because of their reluctance to undergo maintenance dialysis (Jungers, et al., 1993). The significance of the role of patients in affecting their timing of referral to nephrologists will become more apparent in the next chapter, which addresses the relationship between onset status and patient choice of renal replacement therapy.

A third factor influencing the diagnostic process is the primary care provider's willingness to refer patients to a nephrologist. Pre-dialysis kidney patients are generally followed by PCPs, though it has been shown that many nephrologists are the primary care providers for chronic dialysis patients (Bender and Holley 1996). When patients' kidney disease has progressed to a certain point indicative of being end-stage (this will be addressed below in more detail), PCPs have the responsibility to refer such patients to nephrologists who manage the kidney disease.<sup>20</sup> One nephrologist in this study, Dr. Young, explained how interpersonal and interprofessional relationships between nephrologists and PCPs can effect patient referral and education practices in the following way:

"The problem is that we need to develop the infrastructure not only to provide the education but to track the patients. So if they don't need dialysis today, they need it in two months, we need to work with the [primary care] physician to get the access placed without the physician feeling that we're taking over the care right now. You know, it's very difficult to maintain networking with referrals, referring physicians, if they sense you're taking over the care too quickly... There is a real struggle. And the other thing is sometimes we make the primary care physicians feel that they don't have the expertise to take care of them or they've not provided good care or we don't give them good feedback..."

Although the referral practices of primary care physicians are beyond the scope of this study, it is important to note that they inevitably effect the communication process between

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<sup>20</sup> Informal discussions with nephrologists and empirical evidence show that PCPs refer kidney patients earlier than they did ten years ago, but many continue to be late in their timing of referrals (Campbell, et al., 1989; Ratcliffe, et al., 1984). Late referral occurs in approximately 20%-50% of ESRD patients (Ratcliffe, et al., 1984; Jungers, et al., 1993; Campbell, et al., 1989). Studies have found that delayed referral of patients with chronic renal failure to nephrologists incur heavy medical and economic costs to patients and the health care industry (Eadington 1996; Jungers, et al., 1993). The absence of guidelines for referral of patients to nephrologists (Hayslip and Suttle 1995) may account for the high rates of late referral.

nephrologists and patients, and possibly even both of their treatment decisions, as we will see in Chapters 6 and 7. Referral patterns can influence how much time nephrologists have to educate their patients about ESRD (Lameire, et al., 1997; Hayslip and Suttle 1996). Specifically, late referrals generally preclude the possibility for educating pre-dialysis patients about their treatment options.

Once PCPs refer patients to nephrologists to carefully monitor their renal disease, nephrologists must determine when to initiate renal replacement therapy, that is, the transition from predialysis to dialytic care (Churchill 1997). There is considerable debate over defining when kidney patients' renal disease becomes end-stage. The traditional indicators for initiating dialysis have been clinical signs and symptoms including nausea and vomiting, fatigue and weakness, cognitive dysfunction, depression, pruritus, and even poor interpersonal relationships<sup>21</sup> (Hakim and Lazarus 1995).

Since not all patients exhibit these signs and symptoms to the same degree, (which introduces variability in the timing of referral among patients), nephrologists rely on two standardized, systematic measures of glomerular filtration rate (degree of kidney functioning) namely, serum creatinine and creatinine clearance.

A transplant surgeon on the Internet succinctly explained how these two measures work. Serum creatinine (Scr) is a protein excreted by muscle into the blood. People produce a generally stable amount. "The creatinine *level* in the serum is therefore determined by the rate it is being removed, which is roughly a measure of kidney function." Normal Scr is about 1.0 for an average adult. The lower the Scr, the better the kidney functioning. The second measure,

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<sup>21</sup> According to Hakim and Lazarus, physicians make this judgment based on patients' subjective self reports of uremia. However, they note that "There is an increasing need to identify objective criteria for such a decision" (1995:1319).

creatinine clearance (CC), is “technically the amount of blood that is ‘cleared’ of creatinine per time period.” This is usually expressed in milliliters (ml) per minute. The normal CC is 120 ml/min for an adult. Creatinine clearance is “roughly, inversely related to serum creatinine: if the clearance drops to one half of the old level, the serum creatinine doubles (in the steady state).” For adults, a rough association can be made as follows: Scr of 2 is roughly a CC of 60 ml/min; Scr of 4 is roughly a CC of 30; Scr of 8 is roughly a CC of 15. A CC of 15 means that only about 15% of the kidneys remains functioning.

The debate about defining ESRD has centered on determining which Scr and CC numbers are the best indicators of renal failure. UNOS has established a policy that patients must have a CC of 20 ml/min or less to be wait-listed for a kidney transplant.<sup>22</sup> Traditionally, the creatinine clearance at the time of dialysis initiation has been less than 10 ml/min (Churchill 1997). An evidence-based review of studies evaluating the medical effects and outcome of early versus late initiation justifies a creatinine clearance of 9 to 12 ml/min (Churchill 1997). The disparity in perceived appropriateness of levels of Scr and CC was also apparent in the responses provided by nephrologists in this study. This issue will be discussed further in Chapter 6.

### **Treatment Options for ESRD**

Kidney failure is treated with a form of renal replacement therapy, a special diet, and medicines. All treatments are in part determined by each patient’s special needs, age, type of kidney disease, comorbidities, state of health, and lifestyle (The Tri-State Renal Network 1996).

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<sup>22</sup> UNOS’ policy on creatinine clearance changed during the course of fieldwork. UNOS had initially required a CC of 15 for diabetics and a CC of 20 for nondiabetics to be eligible for transplantation. It was originally thought that diabetics were ‘sicker’ than other patients with kidney failure because their disease progresses more quickly, thus the necessity of wait-listing them early, before they become too sick to get a transplant. However, UNOS changed the CC to 20 to facilitate a level playing field in access to transplantation for all patients regardless of their ESRD etiology.

There are three main forms of renal replacement therapy for ESRD: hemodialysis (60%), peritoneal dialysis (10%), and kidney transplantation (30% of patients) (USRDS 1998). Hemodialysis uses a dialysis machine and an artificial kidney to filter metabolic waste products and excess fluid from the blood. Dialysis is based on the chemical process of diffusion and osmosis by which some molecules from one container pass through a permeable membrane into another container. It involves the surgical placement of a “shunt,” a connection formed either by one’s own veins or artificial material between the arterial and venous veins to create an avenue for a large passage of blood to flow through the artificial kidney which is pumped by the dialysis machine. Shunts are preferably located in the arms, although they can be placed in the femoral artery or neck if there are problems with accessing it. Hemodialysis can be performed at home or, more commonly, in a dialysis center (USRDS 1998), where technicians and nurses insert and remove the needles and monitor blood pressure and fluid loss throughout the process. In-center dialysis involves three to five hour shifts three times a week, depending on the size of the patient. Larger patients require longer dialysis because of the greater blood volume to cleanse.

Peritoneal dialysis (PD) involves inserting a tube through the abdomen into the peritoneal cavity. Like hemodialysis, PD cleans the blood, but does so by filling the peritoneal cavity with dialysate and allowing osmosis to occur over a thirty minute period. PD is done by the patient, and exchanges of the dialysate fluid and its removal occur four to five times per day. The advantage of PD is that it can be performed independently and according to the patient’s personal schedule. One drawback of PD is that boxes of sterile materials needed for the exchange take up much room in one’s home environment.

The alternative to dialysis is kidney transplantation. A transplant nephrologist in this study, Dr. Julian, estimates that only 30%-40% of ESRD patients are eligible for a transplant.

There is consensus in the dialysis and transplant community that kidney transplantation is a better form of therapy for ESRD than dialysis because it improves quality of life and allows for a longer life expectancy than does dialysis (Evans, et al., 1985). Either a living- (related or non-related) or cadaver-donated kidney is surgically transferred into the patient. Patients have higher chances of getting a better kidney match with a living (related) donor than a cadaver donor.<sup>23</sup> With a transplant, patients do not require dialysis since the new kidney performs all of the functions of the old kidneys. A transplant social worker, George, used a car metaphor to convey his view that transplantation is the best form of treatment that involves fewer problems than hemodialysis or peritoneal dialysis:

"When you're on hemodialysis, you're basically driving a Chevy. You have a good usable car that will get you where you're going and it works. And if you go to peritoneal, you're going to go up to a Buick, maybe a little bit better model. But when you get a transplant, you're going to get a Cadillac. Now let me tell you what I'm saying. You're going to get the best of the line form of treatment that we currently have, and I'm not going to pretend different. It is to me, to my way of thinking the best one to chose. However, please know, we're not giving you a jaguar, we're not giving you a Mercedes, we don't have those... I mean I see it, people's lives are better: dietary, food, so it's not trading for one set of problems. It's trading up, you're trading up. You're going to get a better system, if everything goes all right, which it usually does."

Hemodialysis and transplantation have advantages and disadvantages. The advantages of hemodialysis are that it is predictable (it takes less time to do than PD), trained professionals are with the patient throughout treatment, and patients can get to know other patients. The disadvantages of hemodialysis are that it requires needle sticks three times a week, treatment is scheduled by the dialysis center, and patients must travel to the center for treatment. In addition, patients experience many medical and physical problems associated with dialysis, see Table 3.1 for a review of these problems.

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<sup>23</sup> With full siblings, patients have a 25% chance of being perfectly matched on all 6 antigens, a 25% chance of not matching on any of the antigens, and a 50% chance of being matched on 3 of the 6 antigens (Dialysis Listserv 6-30-97). The average antigen match with siblings is 3, and parents almost always match exactly 3 antigens with their children (Dialysis Listserv 6-30-97).

**Table 3.1 Problems associated with hemodialysis<sup>1</sup>**

Blood leaks at the needle sites
Low blood pressure due to:
-- loss of blood as it fills the dialysis lines and artificial kidney at the beginning of treatment
-- loss of water in blood near the end of treatment
Muscle cramping of the hands, feet, legs due to removal of fluid and waste products
Greater risk of infection because:
-- white blood cells are slow to attack bacteria or viruses
-- presence of open wound at access sites
Fluid overload: Because patients have minimal or no capacity to create urine, fluid builds up in the body between dialysis treatments. While dialysis removes the excess fluid from the body, excess fluid gains can be harmful because they lead to increased blood pressure, swelling of extremities (edema), and shortness of breath. This can ultimately result in congestive heart failure and lung congestion.
High blood pressure due to:
-- high fluid intake
-- eating too much salty food
Anemia (or weak blood) is caused by:
-- the reduced number of red blood cells. Healthy kidneys produce a hormone called erythropoietin which stimulates bone marrow to produce red blood cells. Patients with kidney failure no longer make this hormone
-- iron deficiency because the body does not absorb enough iron
-- blood deficiency
-- Signs of anemia are tiredness, feeling cold, and angina
Nervous movements: Kidney patients have weakening nerve function called neuropathy. Symptoms include restless legs, tingling or burning sensation of the feet, weakness of the legs and arms
Bone disease: This is caused by the imbalance of the body's calcium and phosphorus levels. High levels of phosphorus lead to reduced amounts of calcium because it leaches calcium from the bones, resulting in the weakening of bone structure.
Itching is caused by various factors:
-- dry skin -- since sweat and oil producing glands work poorly in dialysis patients)
-- high calcium-phosphorus levels
-- high blood levels of parathyroid hormone
-- allergic reactions

1. Adapted from: The Tri-State Renal Network 1996:12-15.

The advantages of transplantation are that it works like a normal kidney, it helps recipients feel healthier, it involves fewer dietary restrictions, and there is no need for dialysis. The disadvantages of transplantation are that it requires major surgery, patients may need to wait for a donor, one graft may not last a lifetime since rejection may occur, and patients need to take immunosuppressant drugs as long as the transplanted kidney still functions. These drugs carry the risks of cancer and other side-effects. Another type of disadvantage is cost. Transplantation incurs on patients greater costs than remaining on dialysis. The estimated charge in 1996 dollars for a kidney transplant for the first year is \$116,100 and for the estimated annual follow-up is



\$15,900 (UNOS 1997a:20). Compared to six other types of organ transplants, kidneys cost the least amount for the first year charge and the second to least amount for annual follow up charge. These costs include: transplant evaluation and testing, transplant surgery, and follow-up care, lab tests, and medication. Medicines for kidney transplantation cost between \$1,000 to \$2,000 per month, depending on the dosage of medicine.

As “halfway technologies,” dialysis and transplantation are expensive treatments that *sustain* life but do not *cure* an underlying chronic disease (Moskop 1987; Behney and Sisk 1984). “Cure” implies an elimination of the cause of the disease (Behney and Sisk 1984). Since transplants last for a limited amount of time, after kidney rejection, patients return to the need to treat ESRD. The notion of halfway technology can be framed in another way: contrary to the tenet of medical ideology that technologies eradicate illness, the technical interventions of dialysis and kidney transplantation have created the disease entity ESRD (Plough 1981). For without this technical intervention, patients with renal failure will die. According to one transplant surgeon on the Internet, of all kinds of end-stage organ failure patients who want a transplant, kidney patients make up 99.9% of those who decide not to have a transplant because they have dialysis to fall back on, instead of death.

Dietary restrictions are an essential part of maintaining health for patients with kidney failure because of the build up of wastes in the blood. Patients eat controlled amounts of foods and fluids. For instance, patients must limit and balance the amounts of sodium, potassium, and phosphorous they ingest. In addition, most patients are required to eat a large amount of protein because dialysis leeches it out of the body. While a healthy person needs 0.8 grams of protein, a kidney patient needs 1.2 grams of protein per day. Protein is important because it helps fight infections and without enough, patients may not be able to go to surgery. Patients must also limit

their fluid intake. One rule of thumb is to take in 1000 cc's of liquid (a little more than a quart) plus an amount equivalent to output (urine) per day.

Patients must also routinely take medications to help keep the chemicals in the body in balance between dialysis treatments (The Tri-State Renal Network 1996). The median number of medications among incident and prevalent non-diabetic HD patients in 1996-1997 was eight (USRDS 1998). Of the incident HD patients in 1996/1997 (n=1,998), medicines commonly prescribed include: antihypertensives (75%), cardiovascular medications (22%), calcium and phosphorus balance (78%), erythropoietin and iron (83%), gastrointestinal agents (30%), analgesics (12%), antithrombotic agents (18.5%), endocrine/hormonal agents (for diabetes) (68% among patients with diabetes as the cause of ESRD under age 65; 6% among patients with causes of ESRD other than diabetes under age 65), psychiatric medications (12%), and vitamins (64%) (USRDS 1998).

There are other treatment options available to ESRD patients though nephrologists do not necessarily recommend using or doing them as the primary form of treatment. Patients may try alternative methods of treating their kidneys, including herbal remedies, acupuncture, etc. (Snyder 1983). While few patients use alternative medicines alone (and those who do so tend not to use them for very long), many will use them in conjunction with dialysis therapy or transplantation.

Patients also have the option of no treatment or to withdraw from dialysis, which would inevitably lead to death (Sehgal, et al., 1996; Wight 1993). The number of patients who electively withdraw from dialysis falls between 4% and 22% (Eggers 1990; Leggat, et al., 1997). An article reviewing the literature on patients who withdraw from dialysis, with the understanding that they will die, showed that "blacks" withdraw themselves from dialysis 1/3

less often than “whites”; diabetic patients in these “races” have highest rate of withdrawal (Leggat, et al., 1997; Eggers 1990; Chazan 1990). The reasons for withdrawal are access failure, failure to thrive, and medical complications. The rate of withdrawal increases as age advances for all people.

### **Population**

In 1996, there were 283,932 patients treated for ESRD (USRDS 1998). The ESRD prevalence is 1,072 per million population (pmp), and increasing 8% per year (USRDS 1998). See Table 3.2 for a listing of the sociodemographic characteristics of the ESRD population. The prevalence of ESRD varies not only within the US but also among the countries of the world (Chugh and Jha 1995; Nissenson, et al., 1993). For example, in Australia, there were 590 ESRD patients pmp in 1996 (USRDS 1998).

**Table 3.2 Treated Medicare ESRD point prevalence counts and rates<sup>1</sup> by age, sex, “race,” and primary diagnosis, 1996**

Characteristic <sup>2</sup>	Count <sup>3</sup> (n)	Percent of Total	Rate per Million <sup>3</sup>
Age 0-19	5,180	1.8	64
Age 20-44	73,734	26	692
Age 45-64	109,834	38.7	2,280
Age 65-74	58,549	20.6	3,518
Age 75+	36,635	12.9	2,715
Female	130,551	46	883
Male	153,381	54	1,233
“White”	173,443	61.1	754
“Black”	91,580	32.3	3,404
Asian/Pacific Islander	9,863	3.5	1,291
Native American	4,504	1.6	2,761
Other/Unknown	4,542	1.6	n.a.
Diabetes	92,211	32.5	339
Hypertension	69,538	24.5	256
Glomerulonephritis	50,378	17.7	185
Cystic Kidney Disease	13,454	4.7	50
Total	283,932	100	1,041

1 Source: USRDS 1998. Rates are adjusted for age, sex and “race.” Rates are computed relative to the corresponding population for age, sex, and race results. Preliminary.

2 Patients with other or unknown race are excluded from rate analyses. Other urologic, other unknown, and missing cause of ESRD are included in the total but are not shown.

3 Counts and rates do not include patients from Puerto Rico or US Territories.

### Dialysis patients

The number of patients in the US receiving in center hemodialysis in 1996 was 175,959, which accounted for 85% of all dialysis patients (USRDS 1998). In 1996, in center hemodialysis patients accounted for 79.6% of dialysis patients in the Network (USRDS 1998).

### Transplant patients

As of August 26, 1998, there were 40,715 registrations on the National Transplant Waiting List for a kidney transplant, and 1,770 registrations for a kidney-pancreas transplant (UNOS 1998c). In 1997, 38,236 patients were registered on the National Transplantation Waiting List, but only 11,409 (30%) patients received a kidney that same year (3,628 from living donors) (UNOS 1998a,b). The total number of kidney transplants performed increased from 6,112 in 1983 to 11,902 in 1995, representing an average annual increase of 5.7% (HCFA 1997). Living-related donors have comprised about 20% of all kidney transplants performed annually in the US, this percentage has remained constant for the last ten years (National Kidney Foundation 1993).

Demographic factors associated with high rates of transplantation include younger patients, males, and European-Americans (USRDS 1998). See Table 3.3.

**Table 3.3 ESRD treatment modality (%)<sup>1</sup> by age, sex, “race,” and primary disease, 1996**

Patient Characteristic	N	Functioning Transplant	Center HD
All patients	287,515	27.4	61.2
Age 0-19	5,233	66.8	16.9
Age 20-44	74,567	47.9	41
Age 45-64	111,576	30	58.1
Age 65+	96,139	6.3	82.8
Male	155,514	30.2	58.9
Female	132,001	24.1	63.9
“White”	175,745	34.3	53.3
“Black”	91,981	15.3	75.5
Asian/Pacific Islander	10,099	26.4	60.3
Native American	4,509	19.7	67.6
Other/Unknown	5,181	18.7	68.9
Diabetes	93,601	17.8	70.1
Hypertension	70,199	15.5	73.8
Glomerulonephritis	51,176	43.3	44.6
Cystic Kidney Disease	13,593	47.8	40.7
All Other <sup>2</sup>	58,946	38.4	51

1 Source: USRDS 1998. Percentages add across, they do not add up to 100 here because other dialysis submodalities are not included in this table.

2 Includes other known, uncertain, and missing causes.

### Survival statistics

In 1995, the death rate of dialysis patients was 23% per year (USRDS 1998). See Table 3.4 for the percent of patients living on dialysis and transplantation after 1, 3, and 5 years of ESRD. The longest number of years of continued functioning for a living adult cadaveric kidney recipient is 31 years, 11 months; and 29 years, 11 months for a living-related kidney, as of 1994 (Terasaki and Cecka 1994).

**Table 3.4 Percent of patients alive on dialysis and transplantation at 1, 3, and 5 years after beginning renal replacement therapy, 1994<sup>1</sup>**

Treatment	1 year	3 years	5 years
Hemodialysis	78.7	50.6	33
Transplant patient survival			
cadaver donor recipients	93.7	87.4	79.9
Living donor recipients	97.1	93.7	89.6
Kidney graft survival			
Cadaver donor recipients	83	72.2	61.7
Living donor recipients	91.5	84.4	76.3

1 Source: HCFA 1997.

People die not from ESRD but from complications of treatment. The causes of death in patients with ESRD reported by the US Renal Data System are comorbidities, primarily cardiovascular disease, and infectious diseases (Perneger, et al., 1993). Evans, et al., (1981) found that comorbidities are extensive in the ESRD population: 39% of all ESRD patients have major cardiovascular disorders (angina, myocardial infarction) and 28% have musculoskeletal disorders (bone disease). See Appendix V for data on the expected remaining years of life of ESRD patients.

### **Financial Coverage**

This section reviews the various forms of insurance coverage for dialysis and kidney transplant patients. The most common sources of funding for kidney transplantation are public: Medicare and Medicaid, while the less common sources are private: insurance, charitable organizations, advocacy organizations, and fund raising campaigns (Evans 1991). There is a difference between insurance coverage and reimbursement: whereas coverage denotes the types of items and services an insurer pays for, reimbursement refers to the monetary amount an insurer is willing to pay for a covered item or service (Evans 1991).

When patients' renal disease is officially considered end-stage, Medicare begins financial coverage for dialysis treatment for eligible patients. Medicare is a federally-funded health insurance program that funds those age 65 and over, the disabled, and dependents of Medicare beneficiaries (Evans 1991; UNOS 1997a). Eligibility for Medicare entitlement requires individuals to be diagnosed with ESRD and be fully or currently insured under Social Security (Rettig 1991). It is estimated that 6 to 7 percent of the ESRD population is ineligible for

Medicare because of insufficient past labor-force participation to be insured by Social Security (Dennis 1995:94).<sup>24</sup>

ESRD is the only disease category singled out in the US for special federal funding. In September 1972, Congress passed legislation, the Chronic Kidney Disease Amendment to the Social Security Act (Public Law 92-603) that extended Medicare benefits to essentially all ESRD patients who were not employees of the federal government and who were not covered by Veterans Administration benefits (Evans, et al., 1981). This law went into effect starting July 1973. Medicare covers more than 90% of the US population on dialysis treatment (Rettig 1991).

Congress was motivated to establish the ESRD program for several reasons. First, the ESRD program was intended to promote patient rehabilitation with the understanding that the program cost would be offset by patients' participation in the labor market (K. Meyer 1995:107; Rettig 1991). The actual costs of dialysis were higher than projected, by three to seven times. Some proponents of the bill proposed that "after an initial cost of \$400 to \$500 million over several years, the restored productivity of ESRD patients would render the ESRD program 'budget neutral'" (Moskop 1987:11). A second reason is that Congress became convinced of the power of dialysis to save lives (Moskop 1987:11). The ESRD program was successful in both increasing the number of people who could benefit from dialysis and in providing equal access to both sexes, all "races," ages, and people of diverse backgrounds (Evans, et al., 1981). For instance, in 1965, there were only about 300 patients undergoing dialysis in the US; this number jumped to 10,300 patients in January 1974 (Evans, et al., 1981). Lastly, Congress justified the universal entitlement for ESRD because of the expectation at the time that national health insurance was imminent (Rettig 1991).

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<sup>24</sup> According to a dialysis social worker, Joanne, patients must have at least a two-year work history to be eligible for Medicare.

Medicare pays a fixed capitated fee for dialysis treatments only. That payment includes equipment, supplies, staff costs, overhead, and some medications, e.g., heparin. Medicare reimburses physicians at \$128 per hemodialysis treatment (Rettig 1991). Medicare covers 100% of the hospital bill for a kidney transplant procedure for the first 60 days, rejection episodes, and 80% of professional fees.

In 1986, Congress expanded Medicare Part B to include coverage for 80% of immunosuppressive drugs for one year. Congress passed the Omnibus Budget Reconciliation Act (OBRA) of 1993 on August 6, 1993 which expanded Medicare Part B coverage of immunosuppressive drugs from one to three years (Colville 1995).

A bill to expand Medicare coverage of immunosuppressant drugs for transplant recipients for life was introduced in the House of Representatives in early 1997. Representative Charles T. Canady (R-FL) introduced the Measure H.R. 1061 in the House to amend Title XVIII of the Social Security Act to eliminate time restrictions on benefits for immunosuppressive drugs under Medicare (TRIO Update 2/1998). The proposed legislation would also have private insurers cover immunosuppressive drug therapy for recipients (TRIO Update 11/1997). Senator Mike DeWine (R-OH) also introduced "The Immunosuppressive Drugs Coverage Act of 1997" (S. 1481) to the 105th Congress (TRIO Update 2/1998). The bill is designed to extend Medicare coverage of immunosuppressive drugs for the life of the graft. This bill failed to pass the Senate in 1997 (UNOS Bulletin 1997a).

Patients who are ineligible for Medicare may receive Medicaid benefits which are administered by individual states (Evans 1991). Patients may qualify for Medicaid if they are eligible to receive cash payments from one of the welfare programs established under the Social Security Act. In this state, individuals qualified for Medicaid in 1997 if they earned an income of



\$418 per month or less with assets amounting to \$1,500 or less.<sup>25</sup> Medicaid covers 100% of in-patient, out-patient, and professional fees, and the entire costs of immunosuppressant drugs as long as patients remain disabled. Private insurers are another source of income for patients. Insurance companies usually pay a percentage of hospital charges. Most companies have a lifetime maximum amount or “cap” which means that the patient is responsible for any additional fees after the patient has reached the cap amount. Transplant recipients without substantial insurance are encouraged to seek funds from charitable organizations and fund raising campaigns.

### **History and Organization of Dialysis Centers**

#### **History of dialysis treatment**

Around 1960 Dr. Belding H. Scribner invented the mechanism, a “cannula and shunt,” to connect a patient to an artificial kidney machine (Macklin 1987). The discovery of the processes of diffusion and osmosis occurred in 1830 by Thomas Graham, a Scottish chemist (McBride 1984; Parsons 1978 in Daniels 1991). Graham coined the term dialysis from the Greek *dia*: through, and *luein*: to loosen (Daniels 1991). The first successful use of an artificial kidney machine was on September 11, 1945 by Dr. Willem Kolff in Holland. The first artificial kidney machine to operate successfully in the US was on June 11, 1948 (McBride 1984). Various permutations of the artificial kidney machine were devised. Today, dialysis is done using a hollow-fiber kidney in which blood flows through semi-permeable hollow fibers and dialysate fluid passes among them.

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<sup>25</sup> In this state, couples qualified for Medicaid in 1997 if they earned a combined income of \$726 per month or less with assets amounting to \$2,250 or less.

### History of selection of dialysis patients

When the artificial kidney machine was invented in the early 1960s only a few wealthy people could benefit from this expensive and scarce technological resource. To aid in patient selection, an anonymous seven-member committee comprised of lay representatives from the community was used to select from all ESRD patients the most medically suitable candidates for hemodialysis on the basis of social worth (Macklin 1987). Social worth factors considered included age, sex, marital status, number of dependents, income, net worth, emotional stability, educational background, occupation, past performance, future potential, and personal references (Macklin 1987). This method of selection resulted in a distinct bias in favor of upper-income, married, job-holding, male patients. The passage of Public Law 92-603 in 1972 entitled everyone to receive renal therapy regardless of financial capacity.

### Organization of dialysis centers

There are 18 ESRD network agencies which monitor dialysis units and transplant centers throughout the US. A network is an agency which monitors the treatment of kidney patients. Congress established the network system to help provide quality care to kidney patients (The Tri-State Renal Network, Inc. 1996).

The “dialysis industry” is comprised of “firms that provide dialysis services through a network of approved dialysis centers” (Daniels 1991:224). There are several renal care provider companies;<sup>26</sup> some are national while others are regional (Daniels 1991). The 1972 legislation increased the demand for hemodialysis such that the number of providers rose from only 250 dialysis centers in 1969 (Evans, et al., 1981) to 1,578 in 1986 (Daniels 1991). The majority of

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<sup>26</sup> As of 1991, renal care providers included National Medical Care, Inc., Community Dialysis Centers, Inc., Medical Ambulatory Care, Inc., Century Dialysis Corporation, Ushawl, Inc., and Security Health Services, Inc. (Daniels 1991).

dialysis facilities (88.7%) were hospital-based, though by 1986, 58% were free standing (Daniels 1991). Dialysis facilities are either for-profit or not for-profit. Since some dialysis centers are for-profit businesses, they refer patients for transplantation less often than not for-profit centers (Gardner 1981). Correlation-regression plots derived from HCFA 1979 data reveal that the more for-profit units there are in a network, the lower its rates of transplantation and home dialysis (Gardner 1981). Thus there is a profit motive for this type of center.

### **History and Organization of Kidney Transplantation**

#### **History of transplantation**

The first long-term successful kidney transplant in the world occurred in 1954 between two identical twin brothers by Dr. Joseph Murray at the Peter Bent Brigham Hospital in Boston (Dennis 1995). Living-related donors were the primary source of donors until 1962, at which time the first immunosuppressant drug, azathioprine, was discovered to allow for the use of cadaveric kidney donors (Dennis 1995). The increased range of donor sources was made possible by advances in immunosuppressant drugs and new laws defining death.

In 1972, J.F. Borel at the Sandoz Pharmaceuticals Corporation discovered a new immunosuppressive drug, cyclosporine, a fungal metabolite (Fox and Swazey 1992). By 1989, it was almost universally given to transplant recipients since it improved survival and decreased postoperative morbidity (Fox and Swazey 1992). Despite its toxic side-effects, cyclosporine has been heralded for its increased efficacy and for making cadaveric transplants possible.

The first human cadaveric transplant was a heart transplant in Cape Town in 1967; the donor was brain dead but with a beating heart, causing society much anxiety over when death occurs. The first definition of death to veer from traditional heart-lung definitions was proposed in 1968 by the Ad Hoc Committee at Harvard Medical School. The Ad Hoc Committee defined

death as irreversible coma in which there is no “discernible central nervous system activity” (1968:337). It took over a decade for this whole brain definition of death to become widely accepted. It was not until 1981 when the American Medical Association and the American Bar Association approved of The Uniform Determination of Death Act (UDDA).

The UDDA advanced two standard definitions of death: individuals are dead if they have undergone either “irreversible cessation of all functions of the entire brain, including the brain stem,” or “irreversible cessation of circulatory and respiratory functions” (in Veatch 1993:18). Most state legislatures subsequently enacted the UDDA’s definitions of death (Fox and Swazey 1992:61). “Viable donors” are those who are considered dead based on brain-oriented criteria, known as heart-beating cadaver donors, since organs must be procured from cadavers with recently beating hearts (Arnold and Youngner 1993). The longer the organ remains outside of the cadaver donor before transplantation, the less useful it becomes because it fails to receive blood and oxygen. This liminal period of time or “warm ischemic time” must therefore be limited (1993:104).

Although the national rate of living (related) donors is not as high as cadaver donors, the use of living donors has increased over the years. Transplant centers are even performing transplants with living non-related donor (LNRD) kidneys, such as spouses and even close friends. Although some transplant professionals tend to be suspicious of LNRDs because of the possibility of coercion and financial incentives to donate, others find that such donors could help meet the high demand for kidneys (NKF 1993; Evans 1989; Levey, et al., 1986).

#### Current organization of transplantation

The United Network for Organ Sharing (UNOS) is a private, not-for-profit corporation dedicated to operating a unified system that “advance[s] organ availability and transplantation by

uniting and supporting its communities for the benefit of patients through education, technology and policy development” (UNOS 1998d). The National Organ Transplantation Act (NOTA) was established in 1984 to oversee organ transplantation policies through the formation of a task force under contact with the US Department of Health and Human Services (DHHS) (Blumstein 1989). This task force, the Organ Procurement and Transplantation Network (OPTN) was established in 1986 with the mandate to distribute organs for transplantation throughout the US, to accredit transplantation centers<sup>27</sup>, and to establish criteria for the selection of “appropriate” patients for transplantation (Spicker 1992; Blumstein 1989). UNOS administers the OPTN.

The OPTN portion of the UNOS database, the OPTN Patient Waiting List, “contains information used by the computer system to match potential organ recipients with available organ donors” (UNOS 1996a). This is colloquially known as ‘the waiting list’ or simply, ‘the list.’ When registered on the UNOS computerized national waiting list, potential recipients are automatically accorded points based on medical and logistical criteria, as stipulated in UNOS policies. Points are assigned through an algorithm according to: time of waiting, quality of human leukocyte antigen (HLA) mismatch, panel reactive antibody status, medical urgency, age, and previous donation of an organ (part) (UNOS 1997b).<sup>28</sup>

A match in blood type is the primary consideration before determining how good of a match a recipient is to the cadaver kidney. Generally, the larger the pool of potential recipients of a blood type, the longer the wait for a transplant, as Table 3.5 shows. After blood type, one of the most important criteria is the quality of antigen mismatch. More points are allocated to

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<sup>27</sup> UNOS defines an “established transplant program” as one that has performed 50 or more transplants of a specific organ and has been in operation for at least two years (Blumstein 1989:26).

<sup>28</sup> The UNOS point system has changed in 1989 from its original inception in 1987 (Startzl, et al., 1987, 1989). Whereas the first algorithm placed greater weight (points) on the waiting time, the current algorithm places greater weight on HLA matching to ensure a better medical outcome.

recipients when they have a greater number of HLA matches with the donor because of the better probability of patient and kidney survival. In other words, HLA make-up is used to estimate the probability of successful organ and patient outcomes. Another factor taken into account is the panel reactive antibody status (PRA) which represents the extent to which patients have become sensitized to foreign antigens. The higher the sensitivity, the greater the likelihood that a patient will reject a given kidney.

**Table 3.5 Patient registrations on the national transplant waiting list by blood type as of 12/31/97<sup>1</sup>**

Blood Type	Number of Patient Registrants	Median Waiting Time	Frequency in the Population <sup>4</sup>
Type O	19,971 (52.2%)	3-5 years <sup>3</sup>	50%
Type A	10,705 (28.0%)	1.5 years <sup>2</sup>	40%
Type B	6,616 (17.3%)	3.64 years <sup>2</sup>	8%
Type AB	944 (2.5%)	6-12 months <sup>3</sup>	very small

1. From UNOS 1998a.

2. From UNOS 1997c (Based on data for 1994 registrants).

3. As estimated by Rose, an AH transplant secretary. Patients with blood type B have a very long wait because it is rare throughout the world and among organ donors (Zihlman 1982:38).

4. As estimated by Dr. Benton, an AH transplant surgeon.

Priority is given to candidates in the order of local, state, region, and nation. This priority system is set up to share organs quicker because organs last only a limited amount of time outside of the body. The longer an organ remains outside of the body, the greater the warm ischemic time and the damage done to the organ. For example, kidneys can remain outside of the body up to 72 hours, though most are transplanted within 48 hours. Prioritizing candidates on the basis of geography helps minimize the warm ischemic time because of the smaller distance needed to transport the organ. UNOS has divided the country into 11 regions.

An organ procurement organization (OPO) is an organization that coordinates the cadaveric organ donation activities of all hospitals within each service area. There are 54 OPOs across the country (UNOS 1997c). The OPO for northeast Ohio is called LifeBanc and it manages the transplant activities of four transplant centers. LifeBanc's procurement area

contains 65 hospitals. There are ten organ procurement coordinators at LifeBanc who coordinate the procurement process and three are on call at any time. Since patients declared brain dead are potential donors, their hospitals are required, under the Required Request legislation of Public Law 99-509 federally amended in 1994 (42 U.S.C. M-1320b-8),<sup>29</sup> to ask the donor's family if they would be willing to donate their relative's organs (Siminoff, et al., 1995).<sup>30</sup> Physicians are also required to contact the local OPO. An organ procurement coordinator (nurse) from the local OPO conducts various tests on the brain dead patient to determine if donation is in fact feasible.

Each time a donor becomes available, a "match run" is conducted on the UNOS computerized national waiting list. That is, the computer program compares the donor information with recipient characteristics stored on the database. Using a computerized matching algorithm, each donor generates a match run -- a unique list of potential recipients. The algorithm was devised according to allocation policies, transplant center acceptance criteria, and local variances. The OPO contacts each transplant center in their local organ procurement area which have patients on the top of their waiting lists, until a candidate accepts the donated kidney.

Currently there are 272 transplant centers in the US (UNOS 1998e). Of these, 250 specialize in kidney transplants in the country, and 9 of these facilities are located in Ohio as of 1998 (HCFA 1997). Transplant centers vary in size, survival statistics, type of organs

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<sup>29</sup> Hospital eligibility for Medicare and Medicaid reimbursement is contingent upon establishing hospital policies of Required Request, as stipulated by HCFA. The Required Request policy was first proposed in 1984 by bioethicist Arthur Caplan. This policy has recently come under attack by some members of Congress because it is perceived as insensitive to approach grieving families about donation (Meckler 1998). The state of Pennsylvania has already had two years of experience with practicing Required Request in its hospitals.

On August 21, 1998, Secretary of the Department of Health and Human Services, Donna Shalala and HCFA passed a new law, "Routine Notification," that requires all hospitals to do two things: 1) report all deaths not only to the state, but also to the local OPO; and 2) specify hospital personnel to become "designated requestors" who will approach families about tissue donation. The local OPO is responsible for training and certifying the designated requesters. Routine Notification was put into effect to increase tissue and organ donation. The policy requires hospitals to become compliant within one year or else they will lose their Medicare and Medicaid funding (Personal Communication, Karin Ormston, LifeBanc Transplant Coordinator, January 26, 1999).

<sup>30</sup> See Siminoff, et al., (1995) and Youngner, et al., (1989) for problems with the required request law.

transplanted, and philosophy and management of care. The size of transplant center ranges from small, medium, to large according to the number of patients transplanted per year. The transplant center size, outcome statistics, and philosophy of patient selection are interrelated: the more selectively a center chooses its transplant patients, the fewer it transplants, and generally the greater the survival data.

Transplant centers also vary in their standards of accepting feasible donors. That is, some centers are more rigid in who they consider as suitable donors so that they will turn down donor organs if they are not entirely perfect for transplantation. Seventy to seventy-five percent of all organs are accepted by the first or second transplant center to which they were offered in 1997 (UNOS Update 1998). There are multiple reasons established by UNOS for transplant centers to refuse acceptance of kidneys; some of the most common reasons for refusal include: recipient is ill, recipient is unavailable, surgeon refused or too busy, poor quality of donor organ, anatomical problems, and poor HLA match (Kallich, et al., 1993:68; UNOS 1996b).

### **Ethos of Transplantation Today**

#### **Defensiveness**

An ethos of defensiveness against outsiders pervades the community of transplant professionals, transplant recipients, and patients seeking transplants. The basis of the defensiveness is the fear of limits to cadaveric and living organ donations. Without organ donation, many people's lives (and businesses) would be lost. One of the most debilitating factors limiting organ donation is misinformation perpetuated by the media and the public, often through "urban legends" (Matesanz and Miranda 1996; Slapak 1997; Garcia, et al., 1997). Negative broadcasts about brain death, organ trafficking, or fairness in access to transplantation can adversely affect public opinions about organ donation. Although the mass media can be



useful in promoting organ donation, it can also be potentially dangerous when it reports wrong or imprecise information (Cuzin and Dubernard 1995). According to medical ethicist Arthur Caplan (1987:18), “Nothing is more threatening to the integrity of the present system for obtaining organs and tissues than the perception that bias and inequity prevail within the allocation process.”

For instance, as an outsider to this community, I was initially met with suspicion by transplant professionals about my purpose in investigating transplantation. During the course of fieldwork, a potentially damaging urban legend about people stealing kidneys spread among the laity.<sup>31</sup> The legend is about a lone traveler in Las Vegas who goes to a bar, has a few drinks which are tainted with a sedative. He wakes up the next morning in his hotel room’s bathtub which is filled with ice and sees a note taped nearby that reads: do not move, your kidneys have been removed, call the following phone number for the emergency room. To dispel unfounded stories as these, UNOS, OPOs, and other transplant-sympathetic organizations engage in rigorous efforts to educate the public about organ donation and transplantation. They work to eliminate public distrust of organ donation by dispelling popular myths such as: the wealthy get kidneys first, the famous get kidneys first, (e.g., Larry Hagman), and “whites” get kidneys first (Childress 1991; UNOS 1998f). The effect of the media on access to kidneys will be examined in greater detail in Chapter 10.

### Concept of the waiting list

Some patients on the National Transplant Waiting List have the impression that there is a top and bottom to this list. Implicit in this perception is that all new patients are placed at the

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<sup>31</sup> One anthropologist of folklore and urban legends, Barbara Mikkelsen, has traced this legend through several permutations since 1991. Barbara and David Mikkelsen “You’ve Got To Be Kidneying,” <<http://www.snopes.com/horror/robbery/kidney.htm>>, 1997.

bottom of the list and work their way up over time. According to one UNOS Scientific Advisory Committee Member-at-large,

"the waiting list is a misnomer of sorts... There might be a better word for the waiting 'list' and in my opinion, it should be waiting 'pool.' The word *list* generates a hypothesis of 'climbing' up to reach the top (such as being number two on 'the list' is in line to be served next) offering false hopes. Everyone in a pool is on equal ground (status) in the public eye"<sup>32</sup>

In actuality, a new and different list of potential recipients is generated for each donor. The patients listed at the top of a generated list could have been waiting for less time than those listed at the bottom because of better antigen matches. By this token, the differences in time waiting promulgate a practice comparable to 'cutting in line.' This practice is unsettling and confusing for some people because it undermines American conceptions of being on a list or a line. There is something reassuring to people in the US about a line -- its order, knowing that one is owed a turn that is guaranteed by obtaining a unique ticket or position mutually exclusive of all other positions. Transplant professionals have likened the 'waiting list' and matching process to a lottery system: "those with the most [HLA] matching win. The sickest patient doesn't matter in waiting." Another transplant coordinator commented that there are better odds in getting a transplant than with winning the lottery. In the next chapter, I review the problems with access to kidney transplantation, notably, how and why kidneys have not been distributed fairly to African Americans, women, and the aged.

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<sup>32</sup> Dale Ester, <dalee@evergreen.com>, "Transplant Centers and Multiple Listings" <dialysis@wugate.wustl.edu>, 15 June 1997.

#### **CHAPTER 4: THE PROBLEM OF ACCESS TO KIDNEY TRANSPLANTATION**

Having defined the clinical nature of ESRD and its treatment options, we are now ready to examine problems associated with ESRD treatment, namely, why some patients face difficulty seeking a transplant. Access to transplantation is influenced by three types of cultural considerations: 1) patient characteristics, including sociodemographics and disease; 2) healthcare professionals' assessments of patients' medical necessity and psychosocial suitability for transplantation; and 3) policies and regulations.

This chapter reviews the clinical and sociological literature on the differences in access to transplantation by "race," while deconstructing this literature's notions of "race" as biologically based. The approach taken here to examine the concept of "race" is best characterized as an analysis of the discourse about the reality, rather than the reality or phenomenon itself (DeVecchio Good 1985). Deconstructing "race" by no means implies that a problem with access does not exist, but rather, it is argued here that the problem with access to transplantation must be reconceptualized as one of ethnicity.

What follows is a description of the ethical and policy foundations of the current allocation system. Understanding how access problems have been examined is important for several reasons: 1) it identifies the ways in which access problems are culturally constructed, 2) an understanding of the cultural nature of the problem allows for a culturally-based approach to its resolution, 3) it provides perspectives on past findings and context for future work, and 4) it throws into relief the gaps in past research which this investigation intends to fill.

Before examining the clinical and sociological literature's explanations of the difficulty faced by African Americans in obtaining transplants, it is helpful to briefly specify some of the key assumptions about "race" maintained by this literature. First, the literature holds that "races"

represent biologically distinct groups of people. Second, we will also see that the literature confuses the concepts of “race” and “ethnicity.” Third, and implicitly, the clinical studies identify people’s “race” according to US notions of phenotype. These assumptions are problematic because they undermine the purported bases of poor access to transplantation. Each of these assumptions will be discussed in greater detail within the context of the clinical perspectives presented below.

### **Patient Factors Affecting the Selection Process**

The fact that treatment for renal failure is publicly funded means that patients have access to several treatment modalities. Very little is known about how patients’ preferences and subsequent decisions effect the decision to seek hemodialysis, peritoneal dialysis, or obtain a transplant. Those interested in a transplant must choose between a living (related or unrelated) donor or a cadaver-donor kidney. While transplants help rejuvenate patients by increasing their sense of freedom, mental clarity, and physical energy (Koch and Muthny 1990; Evans, et al., 1985; Kaplan De Nour 1994), patients may be reluctant to obtain a transplant because of the risk of kidney rejection, fears of the operation, and concerns about substantial side-effects and costs of immunosuppressant medications.

Most studies of ESRD patients’ treatment choices are focused on the choice between peritoneal dialysis (PD) versus hemodialysis (HD) or between home HD versus in-center HD. Studies of patient factors influencing choice of treatment modality between HD and PD have found that nonmedical factors play a significant role in many patients’ decisions. Patients ranked lifestyle considerations higher than medical consequences of a specific therapy (Groome, et al., 1991). Their choices were also highly influenced by input from social workers and nurses, and somewhat by family and friends (Holley, et al., 1991).

One study of “ethnic” differences in treatment confused categories of ethnicity with “race” when they found that African Americans were 56% less likely than “whites” to use PD as initial treatment for ESRD after controlling for demographic, socioeconomic, and comorbid factors (Barker-Cummings, et al., 1995). The authors propose that treatment decisions are influenced by group preferences and/or health professional influences. However, this explanation is problematic because the category “white” is assumed to reflect a putatively homogeneous group of people. In addition, using categories of “race” and ethnicity interchangeably erroneously confuses notions of biology and behavior. These critiques likewise apply to many studies reviewed below.

Two studies found that physicians’ decisions played a role in patients’ treatment choices. A sociology dissertation on the social factors and choice of home or in-center HD found that home HD is the treatment of choice, and physician orientation is believed to play a key role in choice of therapy (Kanter 1985). A study of parents’ choice between home and in-center dialysis for their ESRD children in France found that cultural values of sacrifice and maternal duty were strong factors in physicians’ recommendations and parents’ decisions to have their children dialyze at home (Waissman 1990). (All references to dialysis will mean hemodialysis from here on unless otherwise specified.)

Only three studies have examined patient factors influencing their choice of treatment modality between HD and transplantation. Two studies used self-administered questionnaires and one used a structured interview. One study examined the transplant choices of dialysis patients (n=95) in a single hospital dialysis unit (Holley, et al., 1996). Only patient demographics and previous experience of transplantation were compared. Religious beliefs were found to be associated with the decision to get wait-listed for transplantation only for African

American patients: 69% of African Americans reported “strong religious beliefs”<sup>33</sup> versus 35% of “whites” ( $p<0.01$ ). The study found that fewer wait-listed than unlisted patients reported strong religious beliefs (37% vs. 58%). In addition, patients without a previous transplant indicated that other people influenced their decisions for seeking a transplant: 50% indicated that their doctor, and 42% that their family or friends, thought it would be good for the patient to undergo transplantation.

The second investigation, a report by The National Kidney Foundation (NKF) randomly surveyed individuals who receive the NKF Family Focus Newsletter ( $n=844$ ) (King 1997). The study examined demographic differences among patients by treatment modality, how treatment options were presented, patient satisfaction, and patient movement between modalities. The study found that some patients wish to change their treatment modality: of 610 responses, 26.4% of patients on dialysis wanted to change their treatment modality (King 1997). The only reason the study specified for changing treatment was personal dissatisfaction.

A third study conducted interviews with new dialysis patients ( $n=48$ ) to determine the extent to which patients were involved in choosing their treatment modality (Tiedke, et al., 1992). The study found that 65% of the patients reported that their nephrologist had chosen the modality for them. The patients’ nephrologists explained that 60% of the patients had been last minute referrals (beginning dialysis within one month of preparing patients for dialysis by surgically inserting a shunt). In that situation, nephrologists had advised patients to receive one form of dialysis with the option of changing modalities after a patient stabilizes. Experience at that free-standing dialysis program indicated that patients remain on the modality used to initiate dialysis, and are not inclined to change modalities.

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<sup>33</sup> Holley and colleagues did not define what they meant by “strong religious beliefs” or explain how they measured it.

The latter two studies presented contradictory data regarding the stability of patients' modality choices. Sociological studies of the ESRD population have also shown that patients occasionally change their treatment modalities, but they neglect to explain the basis for patients' decisions (Gerhardt 1986; Kutner, et al., 1986). One study found that ESRD patients often undergo or use treatment modalities sequentially, and up to seven changes of treatment (sub-)modality have been reported for the first 24 months (Gerhardt 1986:190). Another study has shown that of 97 ESRD patients, more than half (n=50) remained on in-center hemodialysis and did not change their treatment modalities over a three-year period (Kutner, et al., 1986).

My research tracked patient's changes in preferences for hemodialysis or transplantation, as will be discussed in Chapter 8. Identifying why patients change their treatment options and how often they change them is important for assessing their understanding of treatment modalities, notions of "risk" associated with treatment, and their views of healthcare professionals' perspectives on treatments. Obtaining this information can facilitate better understanding of the potential differences in reasoning about treatment by patients and healthcare professionals which could ultimately aid in educating both groups of people.

Several shortcomings are apparent with the first two studies' methods. The study by Holley and colleagues (1996) identified patients who had decided on transplantation as those who have been referred to a transplant center. However, it excluded from the study those who had decided to seek a transplant but had not yet been referred. The study also found differences in decision making between patients with and without a prior transplant. Past transplant experiences have been shown to affect decision making (McCauley, et al., 1989). King's (1997) study used a mailed survey of a self-selected sample. None of the three studies conducted an in-depth examination of patient factors influencing choice of treatment modality. Patients'

treatment decisions will be examined at length in Chapter 7 because they were found to play a role in patients' access to transplantation. In addition to treatment decisions, patients in favor of transplantation must decide whether to accept a living donor offer.

### **Living (Related) Donors (LRDs)**

Patients who desire a transplant may have a preference about the source of the kidney. Patients who prefer a transplant from a living donor may have family members who are unwilling to donate a kidney because of fear of surgery, concerns about future finances, and family pressures to not donate (Starzl 1985; Kreis 1985).

The preferred source of the donated kidney ultimately affects how long patients wait for a transplant. Conversely, the length of wait may effect preferences of donor source. Patients who obtain LRD kidneys are not wait-listed and can be transplanted as soon as they and a suitable donor are evaluated, which takes on average two to three months. In contrast, as noted in the previous chapter, the length of time patients must wait for a cadaver kidney may take several years, depending on various factors.

Few studies examined differences by "race" and gender and even fewer examined differences by ethnicity in who receives living-donor kidneys. Living donors represented 28% of all national kidney and kidney-pancreas transplants in 1996 (UNOS Bulletin 1997b). One study found that "white" males receive LRD kidney transplants five times more often than "black" males, and "white" females receive LRD kidneys four times more often than "black" females (Ojo and Port 1993). However, the investigators reported that factors in the patient, family, religion, society, healthcare professionals, and medical institutions may account for disparities in LRD rates.



African American patients may face difficulties obtaining LRD kidneys because of cultural reasons. First, they have been found to be less likely than “Caucasians” to donate a kidney to a relative (Salvatierra 1989; Gaston, et al., 1993). There are also reports that “blacks” are reluctant to accept LRD kidneys (Jonasson 1989; Lawlor and McElroy 1987). Second, African Americans’ reluctance to accept a LRD kidney may be related to their reluctance to donate a cadaveric kidney. Notably, “blacks” are two-thirds less likely to donate cadaveric organs than “whites” (Callender, et al., 1982) (see discussion below), and, the family refusal rates to donate cadaveric kidneys for “Blacks” (45%) and “Latinos” (43%) are significantly higher than for “Whites” (17%), as reported in three large urban cities (Perez, et al., 1988). While the studies above use “race” terms, it seems as though they intended to use ethnicity terms because of their focus on behavioral rather than biological explanations in patterns of donation.

Unlike the clinical studies above, the following study appropriately used the term “ethnicity” to examine living donor decisions. Griffin and Bratton (1995) conducted a qualitative study in a rural Southern state that examined the attitudes of twelve African American potential donor relatives about living donation. They found that while most relatives considered themselves to be religious, they did not know their church’s views on living donation (58%) or cadaveric donation (67%). In addition, only half said they would donate if asked to by a relative. Some of the quoted reasons why they did not want to donate include: “What I was born with, I’d just like to go out with” or “there’d be no one else to take care of my wife” or “I am too old.” In addition, the majority indicated concern about the donor’s increased vulnerability to sickness or premature death, fears of surgery, and concerns about the expense of the operation, e.g., “I can’t be out of work for a month. Who would pay the bills?” Respondents were reluctant to give organs because of past problems with the health care industry, preferences for donation to other

African Americans, and fear of racist donation practices. The major finding is that African American ESRD patients tend not to ask family members to undergo tests as potential donors: while family members wait to be asked, healthcare professionals wait for the family members to come forth to be tested.

A study using a mailed survey of transplant professionals at transplant centers investigated how institutional factors influence the likelihood of living kidney transplants (Sofaer, et al., 1997). They found that fewer than half of the centers (n=211 out of a total 223 kidney transplant centers) routinely send educational materials about the option of using LRD to potential recipients prior to the first visit. About 40% reported that their center sends no materials. While the transplant community was generally supportive of using LRD, transplant professional groups varied in the extent of their support: more medical directors and transplant coordinators strongly supported using LRDs than did psychosocial services coordinators. The centers where transplant coordinators and psychosocial services coordinators held positive attitudes towards using LRD were likely to perform LRDs at a higher rate. The mean rate of adult LRD transplants conducted at all kidney transplant centers was 23% for the period 1992-1994. Chapter 8 examines patients' attitudes about accepting and asking for kidneys from LRDs as a patient factor influencing access to transplantation.

### **The Current Process of Selecting Patients - Formal Criteria**

Patients electing transplantation are evaluated for suitability by different healthcare professionals in three phases: 1) Nephrologists refer patients to a transplant center or the patient can refer him/herself; 2) The transplant team members, consisting of transplant surgeons, nephrologists, coordinators, and social workers, individually evaluate the patient's medical and psychosocial suitability for transplantation; and 3) The transplant team, as a group, decides which

marginal patients to place on the national transplant waiting list. At each step of the process the patient can decide to accept or reject the healthcare professional's recommendations. Let us first review briefly the nature of clinical research conducted on access issues and then describe how access problems are compounded by nephrologists and transplant professionals.

Research examining factors influencing access to kidney transplantation has mainly focused on racial disparities within the evaluation process and has used mostly secondary databases derived from chart reviews. Eggers (1995) examined access to transplantation using three measures: time from renal failure to transplant, time from renal failure to wait listing, and time from wait listing to transplantation. Eggers found that "black" ESRD beneficiaries fare worse than "white," Asian-American, or Native-American ESRD beneficiaries in all three measures. Eggers also found that although "blacks" made up over 33% of the ESRD population, they received only 21% of the transplants.

Held, et al., (1988) analyzed the effect of patient and dialysis unit characteristics on access to kidney transplantation to determine if "racial" and income differences continued to have an effect on access. Using individual patient data from a systematic random sample of 14,721 new dialysis patients from 1981 to 1985, and aggregate data from a 1984 census of 1,133 dialysis and transplant units, Held and colleagues found that compared to other kidney patients, "white," male, young, nondiabetic, and high-income patients treated in smaller dialysis units were more likely to receive a cadaveric transplant under Medicare. They also found that "blacks" were only 55% as likely as "whites" to receive a kidney transplant when controlling for sex, income, and size of referring dialysis unit. Compelled by this difference by "race," Held, et al., suggested seven possible explanations for their findings.<sup>34</sup> With this study we begin to see that

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<sup>34</sup> These explanations include: 1) medical suitability for transplantation – medical contraindications to renal transplantation may be disproportionate between the "races," and "blacks" may have a higher panel reactive antibody

clinical investigators implicitly view “races” as distinct biological categories. An analysis of the problems inherent in the use of “race” will be presented after the clinical literature is reviewed in this section so that the reader can obtain a full sense of how the literature interprets access problems from a “racial” perspective.

There have been few studies examining the criteria used by nephrologists to refer patients to transplant centers. The Office of the Inspector General’s (OIG) (1987) report examined data on the referral patterns to transplant centers of selected dialysis facilities located in three ESRD networks. Dialysis facilities were found to vary in their referral rates: some facilities had referral rates of 15% or more, while others referred well below the national average of 11.5%. The Inspector General identified three factors contributing to low referral rates. The first problem is that even though legally required under Medicare conditions of coverage, some dialysis facilities fail to develop long term care plans which inform patients about their suitable treatment options for ESRD. Developing these plans yearly is necessary to facilitate change in treatment modality if patients so desire. The second related problem concerns the potentially biased content of these discussions. Physician and nurse educators can unconsciously bias their discussion of treatment options. This is known as “steering” patients to one therapy or another, through the tone and length of time spent discussing each option (Campbell 1991; Kosky 1990). The third problem

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than “whites,” thereby precluding transplantation; 2) geographic access – the location of transplant centers in the US may be a barrier to access; 3) income and health insurance -- Medicare pays 80% of the cost of immunosuppressive drugs for one year (now 3 years) after transplant. Some patients do not have the economic resources to pay for the drugs and other health care costs that transplantation incurs; 4) access to the waiting list -- referral to transplant centers by nephrologists and acceptance by surgeons for placement on a waiting list could be influenced by information on treatment alternatives they provide to the patient; 5) match of available organs -- the difference in donation rates between “races” means a disparity in acceptable organs for transplant candidates; 6) patient choice -- “Possibly, blacks, females, and low income people disproportionately prefer dialysis over transplantation for some reason, although such suggestions verge on stereotyping”; and 7) subconscious bias -- discrepancy in transplant rates may reflect bias on the part of medical staff. Without explanation, Held, et al., excluded from their analyses factors they contend “merit further analysis,” including: patient’s preferences for dialysis versus transplantation, how patients’ social identities affect medical judgments of suitability for transplantation, and characteristics of the medical system in the process of patient education, referral and evaluation.

concerns the failure of nephrologists to refer patients for transplantation to prevent losses in earnings (Office of Inspector General 1987). While kidney transplant surgeons report that at least 20%-25% of the dialysis population is medically suitable for a transplant, only 10%-11% percent of that population is on a transplant waiting list.

A recent study of factors determining the rate of referral and transplantation found that “race” played no role among (n=276) eligible female dialysis patients (McCauley, et al., 1997). However patients with high school or greater education were almost twice as likely to be referred than those with grade school education (p=0.0001). In addition, declining the transplant option was the most common reason for not referring patients. My research examined nephrologists’ styles of educating patients about their renal replacement options and of referring patients to transplant centers to identify whether and how possible biases in such discussions occur. The possibility of nephrologists framing the treatment options will be discussed in Chapter 6 as a sociocultural factor influencing access to transplantation.

Subsequent research has focused on actual practices of distribution and access to a transplant once patients have been placed on the waiting list for a kidney transplant. The OIG’s (1991) report examined the distribution of cadaveric kidneys from the point of procurement to the point of transplantation. Data were drawn from various sources including, a data base of 17,556 individuals in the US who were waiting for or received a first kidney transplant between October 1987 and March 1989, on-site reviews of organ procurement organizations in four states, interviews with transplant professionals, and literature reviews. The Inspector General found that “blacks” waited almost twice as long as “whites” for their first transplant (13.9 months compared with 7.6 months). This “racial” differential remained even when blood type, age, and

immunologic and geographic factors were controlled, which raises the question of whether unconscious biases played a role in allocation decisions.

Sanfilippo, et al., (1992) examined factors that could account for “racial” differences in waiting time among cadaveric kidney transplant candidates. Using UNOS data on all US cadaveric kidney transplant candidates between October 1987 and June 1990 (n=23,468), Sanfilippo and colleagues found that patient factors most significantly associated with increased waiting time were immunologic (presensitization to HLA antigens, O or B blood type, repeat transplant candidate, and expression of rare HLA-A or HLA-B antigen phenotypes). In addition, the nonimmunologic factors significantly affecting waiting time included: age -- waiting times were shorter for patients younger than 15 compared to those aged 15 through 44 years (8.4 vs. 12.9 months;  $p<.0001$ ); multiple listings compared to listing at one center (7.0 vs. 13.3 months,  $p<.0001$ ); and “race” -- shorter waiting time for “white” vs. “black” patients (11.9 vs. 15.4 months,  $p<.0001$ ).

Many studies have since ruled out some of Held and colleagues’ proposed explanations for the difference in transplant rates between putative “racial” groups. Whereas most have confirmed that biological factors play a major role in differences in access by “race,” others have reported that the “race-”based differential was due to biologic (blood type and major histocompatibility complex antigens) and socioeconomic factors (Kasiske, et al., 1991). The Rand Corporation examined three unresolved factors hypothesized by Held and colleagues to affect access to cadaveric transplants by “blacks”: patient health status, geographic location, and biologic characteristics (Kallich, et al., 1993). They used data from the ESRD program in Medicare, the UNOS, and data collected from different organ procurement organizations. While the study shows that biologic factors can explain the gap between the “races” in the chances of

receiving a transplant once on the waiting list, the medical indicators do not explain the significant gap in access by “blacks” to transplant waiting lists (Kallich, et al., 1993).<sup>35</sup>

Having presented the clinical studies on access to transplantation, we can begin to more thoroughly examine their problematic assumptions held about “race.” The clinical studies clearly maintain the assumption that “races” represent biologically different groups of people when they compare the HLA patterns within putative “races.”<sup>36</sup> Such comparisons reflect the clinical investigators’ beliefs that members of each “race” have, as a group, a distinctive and common biological make-up (see Zachary 1993; Hurley 1993). Accordingly, it is assumed that it is easy to distinguish “races” by their immunology.

Although certain populations of people share phenotypic similarities, this is the result of many factors, including adaptation to the environment, genetic drift, and interbreeding. Geneticists explain commonalities among local groups as a factor of genetic “clines” (Livingstone 1993). Certain genetic material is shared at a higher frequency in some populations than in others. This makes sense for people who have had a long history of intra-group reproduction. Thus, there are no definitive boundaries to gene pools, and instead, one gene pool gradually blends into another.

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<sup>35</sup> The data also showed that: a) “blacks” were almost 50% less likely than “whites” to be placed on a waiting list at any point in time, even after controlling for age, previous hospitalizations, primary cause of renal failure, or geographic location of the ESRD patient; b) “blacks” were 11.4% more likely than “whites” to be biologically incompatible with cadaver kidneys being retrieved. This difference explains much of the differences in waiting time to transplantation between “blacks” and “whites”; c) there is no foundation for the hypothesis that “blacks” are more likely to be unavailable for the transplant procedure than “whites”; and d) there is no conscious discrimination against “blacks” with ESRD, and that once a patient is on a waiting list, biologic factors may predominate.

<sup>36</sup> In various subspecialties within American biomedicine, there is a growing awareness of the problems with using the category “race” and even “ethnicity” (see Bhopal 1997; Witzig 1996; Caldwell and Popenoe 1995; Hahn 1992; Osborne and Feit 1992). One transplant surgeon even argued that “there are no issues in transplantation related to race. There are only issues that relate to human beings” (McDonald 1989:3411). There is even a growing awareness in the US of the problem with “racial” categories. National Public Radio broadcasted two long segments on the problem with the concept of “race” in general, and with regard to organ transplantation specifically (Saturday, October 24th & 31st, 1998).

A common mistake people make about the relation between “race” and genetics is known as the “pre-Mendelian error”: people believe that complex groups of traits are fixed and transmitted together, e.g., kinky hair, dark skin, and broad nose that characterize the putative “race” called “Negroid” (Montagu 1963, 1974). Geneticist Mendel revealed, however, that genes act as independent units, so genes inherited must be examined individually, not in clusters. As the renown geneticist, Richard Lewontin notes, any human population of the world shares 93% of all genetic material (Krieger and Bassett 1993). Distinctive “races” therefore do not exist because phenotypic and genetic traits found in one population can be found in all others.

The explanation of clines is less applicable in geographic regions where genetic mixing occurs (through interbreeding) among traditionally distinct geographic groups of people. Numerous African Americans, so-called “whites” of the Southern US, and Native Americans are highly mixed as a result of historical conditions (Washburn 1976). Yet Americans tend to attribute the “black” “race” to people of mixed ancestry. This cultural practice corresponds to the “one drop rule” in which at least a small percent of African American “blood” renders one “black,” regardless of appearance and culture and genetics. Myriad transplant studies, however, fail to account for the possibility of mixing in terms of HLA. Further, the studies assume that people classified as “white” are homogeneous genetically. As geneticists Cavalli-Sforza and colleagues (1994) point out, currently within Europe there exist diverse blood groups and genetic patterns as a result of intermixing and history (invasion, rape). Moreover, studies do not use variables to represent people with mixed heritages when statistically tracking their HLAs. By this omission, transplant studies reify “racial” differences and thus bias their results.

Although determining the HLAs of a transplant donor and recipient is done in a blinded manner, determining their social identity is not blinded, but is in fact culturally based. In other



words, because of the high variability in phenotype and genotype within putative “races,” it would be difficult to accurately identify whether recipients or donors are “black” or “white.” This means that transplant studies relying on “race” as a key variable are likely to report erroneous statistics about transplant outcome and allocation among the putative “races.”

We have presented some of the theoretical assumptions clinical investigators make about “race” above. There are also methodological problems inherent in clinical studies reporting results in terms of “Blacks” or African Americans vs. “Whites” or “Caucasians.” This dichotomous categorization is implicitly problem-laden for two key reasons.

First, many different ethnic groups comprise the term “European American.” Thus, comparisons fail to be made on an appropriate theoretical level. That is, their social group comparison is analogous to comparing Empire Apples to a bowl full of Macintosh, Granny Smith, Delicious Red, and other types of apples.

We must recognize, however, that such categories are not the inventions of the research investigators who use them. These categories exist on forms generated by government bureaucrats. As well, there are political motivations for employing “racial” categories, notably to document the presence or absence of discrimination. Yet clinical academicians are not passive in the construction of “race”; they perpetuate the use of these categories and the sense of their reality.

Second, by dichotomizing the samples into two groups, clinical studies fail to seriously consider whether the two groups actually constitute ethnic and/or cultural groups. There is wide cultural variation among people even within the putative “African American” category, and other such ethnic categories, given the differences by geographical location (Southern vs. Northern, urban vs. rural), education, class, religion, etc.

The use of “ethnic” categories is moot unless there can be shown to be cultural similarities among the members of the group. This may be difficult to do for those not trained in cultural analysis since cultural worldviews are shared by people in ways that cut across skin color lines. There are “whites” who identify themselves as “black” (Sunderland 1997) and “blacks” who identify themselves as “white” (Twine 1996). Culture may be found among people who share the same religion, gender, geographic region, etc. But the literature fails to account for such cultural groupings and generally forces the dichotomous categories instead. This results in essentializing conclusions which assume that all people who belong to a social group are alike.

### **The Problem of Organ Donation Among African Americans**

The confusion between “race” and ethnicity is manifested most clearly in the issue of organ donation. As discussed above, clinical investigators have found that immunologic factors play the most significant role in preventing access to transplantation for “blacks.” Specifically, the problem is conceived of as a difference in HLAs between “races”: “blacks” are believed to not share the same types of HLA as “whites” (Milford, et al., 1987; Lazda 1992; Opelz, et al., 1993). The literature claims that kidney donations primarily by “whites” explain the low rate of kidney transplants among “blacks” since few kidneys (only those donated by “blacks”) would be compatible with “black” recipients. Thus it is up to “blacks” to donate more to increase the rate of kidney transplantation among “black” patients.

While this problem is construed in terms of the biology of “race,” the solution to it is framed in terms of ethnicity by its focus on the behavior of a group of people. The following reviews the studies that examine donation among African Americans, though terms of “race” are inappropriately used by the literature instead.

Studies show that “blacks” are subject to disadvantages in organ donation that “whites” do not experience. Though “blacks” comprise 12% of the US population, they make up 30% of the national waiting list of kidney transplant candidates (Callender, et al., 1982). Using HLA antigen matching to allocate kidneys places “blacks” at a disadvantage because only 20% of “blacks” share antigens often found among “Caucasians” (Lazda and Blaesing 1989). Consequently, “blacks” must wait twice as long as “whites” to receive a kidney transplant (Callender 1989). Because less than 10% of organ donors are “black,” cross-“race” donor/recipient matches are more common. In effect, graft survival rates are 10% to 20% lower for “blacks” than for other “racial” groups.

Clinical studies assert that the only options for eliminating discrepancies between “blacks” and “whites” with regard to organ donation and transplantation are to either change the current UNOS kidney allocation algorithm, or increase organ donation among “blacks.” The change in the algorithm is based on the biological notion of “race”: because the allocation algorithm prioritizes medical benefit (via emphasis placed on HLA matching) over equal distribution, it may be unfairly biased against “blacks” whose HLA are seen as uncommon in the donor population. Some healthcare professionals have therefore proposed directing all organs donated by “blacks” to be transplanted in other “blacks” as a form of “affirmative action” (Arnason 1991; Kluge 1989; Opeltz, et al., 1993; Ubel, et al., 1993). Such changes in the algorithm have yet to be made. In contrast, educational efforts targeted toward addressing sociocultural beliefs and values among “blacks,” (perceived in this context as an ethnic group) have been largely successful in increasing potential organ donors (Callender, et al., 1982).

Sociocultural explanations for African Americans’ low donation rate are primarily documented in studies conducted by African American surgeon, Clive Callender and his

colleagues at Howard University (1982, 1989, 1991). In their pilot study, Callender and colleagues found seven reasons why “blacks” are reluctant to grant permission for organ donation: 1) lack of awareness of transplantation, 2) religious beliefs and misperceptions, 3) distrust of the medical establishment, 4) racism, 5) poor access to medical care, 6) lack of appropriate organ procurement specialists, and 7) intra-family relationships. Each of these reasons why African Americans, as an ethnic group, are briefly described below.

Lack of awareness of transplantation. Callender, et al. (1982) showed that many “blacks” were unaware of the urgent need for organs by “blacks.” Callender and colleagues propose that increasing their awareness would increase their donation rate.

Religious beliefs. Studies show that religious beliefs affect “blacks” decisions not to donate (Callender, et al., 1982; Creecy, et al., 1992). Many “blacks” in the pilot study expressed concern that “the body must be kept intact for life after death.” They feared that when Jesus Christ returns, those who donated will be deficient of their organs (ibid.). Another study showed that African and new world Indian views about donating organs are tied to their belief that the dead should not be molested because this may anger their spirits. Receiving a cadaver organ would cause a violation of the body, thus angering the donor’s spirit (Evans, et al., 1986).

Distrust of the Medical Community. Callender and colleagues (1982) found that “blacks” distrust of the medical community is manifested as the belief that after signing an organ donor card, the individual will not receive proper care in a hospital. Many subjects expressed fears of premature declaration of death if a donor card has been signed, and of being vulnerable with only one kidney. There is considerable historical basis to this fear, beginning with forced involvement in medical experimentation as slaves (Dula 1994). Numerous other medical abuses of African Americans have occurred in this century; one of the most prominent

being the Tuskegee Syphilis Experiment, conducted by the United States Public Health Service, which studied the effects of untreated syphilis on “black” men in Macon County, Alabama in the 1950s and 1960s (Jones 1981). Despite the discovery of penicillin, it was not used to aid the “black” men afflicted with syphilis.

Racism. Callender and colleagues (1982) found that “blacks” expressed concern about cross-“race” transplants. Many “blacks” did not want to cross “racial” barriers because they felt the “black kidney” was superior. “Black” donors also sought assurance that their donated organs will be given preferentially to “black” recipients. Similarly, Prottas (1983) found that “black” families believe organ donation only helps “whites,” and “blacks” do not want to help “whites” in this way. Prottas writes:

“How widespread this attitude is impossible to say, but we can’t be too surprised, that in a racially polarized society, altruism is bounded by the limits of racially defined communities even in the absence of specific racial hostility, black donor families may easily have a greater sense of alienation from and fear of the institutions asking them to donate their relative’s organs” (1983:293).

Poor Access to Medical Care. Studies show that “blacks” have poor access to medical care (Blendon, et al., 1989). One reason is because they rely more on emergency rooms and hospital clinics than on consulting physicians at an office (Reitz and Callender 1993). This behavior may result in inadequate communication of health information (Reitz and Callender 1993). Further, inner city hospitals, known for “serving a higher minority population,” are ironically, “the lowest providers of transplant organs” (Plawecki, et al., 1989; Perez, et al., 1988; Merz 1985).

Lack of Appropriate Organ Procurement Specialists. Since 95% of transplant coordinators in the US are not “black” (Office of Inspector General 1991) they may not have an ethnically sensitive approach to educating “black” potential organ donor families (Callender, et al., 1982; Plawecki 1989). These investigators have found that “white” hospital staff often

hesitate to approach potential “black” donor families because they are uncomfortable and unfamiliar with how “black” families react to tragedy (Perez, et al., 1991; Reitz and Callender 1993). African Americans’ grieving behavior tends to be more demonstrative and dramatic (Hines 1991; Perry 1993) than that by some groups of European Americans which are characteristically stoic, e.g., Irish Americans (McGoldrick 1991), White Anglo Saxon Protestants (McGoldrick et al. 1991), the French (Aries 1975), Quakers and Unitarians (Irish 1993), and Jewish Americans (who are neither stoic nor dramatic but rather communicative) (Rosen 1991; Cytron 1993). Due to these types of sociocultural differences, some organ procurement personnel are thus hesitant to approach “black” families and tend to “overselect out’ black families” because they assume that they will refuse to donate given their low donation rate (Prottas 1983:294). This action by hospital staff reifies the “reality” of “ethnic” differences in donating behavior.

Intra-familial relationships. Researchers have speculated that low donation rates among “blacks” may be due to a high rate of them having broken families, single-parent families, or even extended families (Stack 1974): all of these types of families have tended to not donate organs (Prottas 1983; Perez, et al., 1988). Prottas (1983) explains that while extended families involve more complex lines of authority and relationships which makes decision making more difficult, it is likely that the lack of familiarity with “nontraditional” families on the part of the procurement workers accounts for low donation rates. Concordant with this hypothesis, procurement specialists find it easier to obtain donations from tightly knit nuclear families (see Creecy and Wright 1991). Chapter 7 discusses the extent to which African Americans’ reluctance to seek a transplant are similar to concerns about donating a cadaveric kidney.

Again, we see in these sociologically-oriented studies of organ donation, the use of “race” terms when discussing donation behavior, which should really be described by using terms of “ethnicity.” Why then, do so many studies confuse “race” and “ethnicity?” And, why is this confusion perpetuated? These behaviors can be explained in several ways.

First, the investigators -- both clinical and sociological -- who confuse the terms are not anthropologists, thus, they have not been trained to challenge their cultural assumptions about social classification and thus tend to make culturally based distinctions. The use of dichotomized categories “black” and “white” is perpetuated by both the lack of clear understanding about “race” and “ethnicity” and the need to communicate with other academic clinicians whose knowledge of the cultural bases of social categories is likewise limited. In effect, academic clinicians’ uncritical, “scientific” (an oxymoron) use of dichotomous “racial/ethnic” categories reveals little about cultural beliefs and more about the researchers’ own cultural categories. It ultimately shows that they have been seduced by their own constructions.

The second possibility draws upon Edward Sapir’s conception of language and culture, as defined in Chapter 2. It is proposed here that in the US, we do not have the language to describe in ethnic terms the problems and types of people implicit in the “race”-related words. US history abounds with occasions of “racism” and “racial tensions” perpetuated by “racists” -- all of these words and their connotations stand strong in the consciousness of many Americans on an everyday basis. We have the categories and classifications with which to make sense of the term “race” but not “ethnicity.” The word “ethnicist” as a replacement of “racist” has not yet been coined. While the concept of “ethnic cleansing” exists, it has been applied primarily to occurrences outside of the US; if “ethnic cleansing” were to occur within the US, it is likely the

term would be translated as “racial cleansing” because Americans generally think in “racial” terms.

The third reason why “race” and “ethnicity” are used interchangeably pertains to American folk notions of these two concepts. As described in Chapter 1, Americans perpetuate the use of “race” in everyday language through our cultural history and construction of the biological notions of “race.” For instance, many people use “race” terms when asked to identify their ethnic grouping, e.g., calling themselves “black” interchangeably with “African American.” As Blu (1980:204) notes, in American folk usage, the terms “race” and ethnic have separate and overlapping meanings. They overlap in the sense of what she calls “ethnics;” in their sense of “groupness” ethnics share something cultural in common -- a common background, religion, and even “race” (Blu 1980:204-5).

### **Transplant Selection Criteria**

Virtually all research examining racial differences in access to transplantation has focused on differences in waiting time and, to a lesser degree, rates of referral. No research has examined how transplant professionals apply the medical and psychological criteria to evaluate referred patients. The criteria are not cut and dried: transplant professionals deliberate over patients’ financial resources, compliance history, age, family support, and medical and emotional stability.

Kilner (1988) conducted a survey of dialysis center directors (n=373) and transplantation directors (n=80) about the criteria they use to determine whether to select patients for transplantation. He found that the following factors play a significant role in their decisions: psychological stability, age, quality of life, social support, cost of treatment, motivation, and the social value of the patient to society.



Bioethicists emphasize that hidden social worth criteria are contained in the process of selecting potential kidney recipients (Annas 1990). Biases in patient selection are couched in terms of medical criteria (Brock 1988), particularly when differential weight is placed on medical criteria in determining which patients receive kidneys (Brock 1988; Childress 1989).

The relevance attributed to selection criteria demands attention because patients of diverse socioeconomic and ethnic backgrounds differ widely in their abilities to meet expected qualifications for a transplant. For instance, evaluations of patients seeking a transplant may differ because they have diverse kinship structures (Stack 1974) and senses of personal responsibility regarding compliance (Hershel 1992).

Compliance is an important variable to examine because at some transplant centers noncompliant patients are not wait-listed for a transplant (Ramos, et al., 1994). Noncompliance in ESRD patients is common and can be attributed to economic, situational and psychological factors e.g., running out of medicines (Wolcott, et al., 1986). Noncompliance has been shown to be even a form of patient empowerment (Donovan and Blake 1992; Barnhoorn and Adriaanse 1992). Because pre- and post-transplant noncompliance often (61%) results in kidney rejection or death, and frustration for transplant professionals (Douglas, et al., 1996; Schweizer, et al., 1990), some healthcare professionals believe that further treatment (e.g., retransplantation) should be denied to noncompliant patients (Orentlicher 1991).

Consequently, a cultural or ethnic propensity to not comply may result in a diminished likelihood of access to a kidney graft. This research examined how patient noncompliance factors into nephrologists' and transplant professionals' decision making as a possible barrier to access to transplantation. As will be shown in Chapter 10, transplant professionals' deliberations about wait-listing patients are mediated in a social context; the logic governing such decisions

are inherently social and cultural since the ethical values underpinning their logic are shaped by American notions of fairness in distributing scarce resources. Before examining their decisions, it is important first to outline the theoretical underpinnings of justice and microallocation of resources.

### **Ethics and Policy Implications**

In this section we pick up from Chapter 1 and in greater detail consider the distribution of kidneys for transplantation as a cultural process in light of the bioethical concept of justice or fairness. Here we examine the concept of justice as a tool for cultural analysis of how Americans distribute scarce resources and as an American cultural value. This discussion draws heavily upon bioethicists' conceptualizations of "justice" since they have primarily shaped the discourse on it in US health care. It is important to point out that bioethicists' discourse on justly distributing kidneys is formed by observing ethical dilemmas of scarcity.

While transplant professionals do not literally draw upon bioethicists' philosophical discussions of justice when making allocative decisions, bioethicists' analyses are implicitly played out in their deliberations, as will be shown in Chapter 10. Below we will define distributive justice, present different forms of justice as espoused by bioethicists, and consider justice from a cross-cultural perspective. This section then sets the stage for understanding how kidney transplants are distributed according to a culturally-defined sense of justice.

Issues of access to health care are debated using the language of "justice." The principle of justice has been explicated by philosophers by the terms "fairness," "desert" (what is deserved), and "entitlement" (that which one is obligated to provide another) (Beauchamp and Childress 1994). Justice is viewed "as fair, equitable, and appropriate treatment in light of what

is due or owed to persons” (Beauchamp and Childress 1994). Thus, justice can be defined as rendering each person their due.

Distributive justice is the fair and equitable distribution of resources in society. Problems of distributive justice arise under conditions of scarcity and competition (Beauchamp and Childress 1994:327). Organ transplant allocation occurs in what one bioethicist calls “a context of absolute scarcity,” meaning that the demand entirely outweighs the supply (Koch 1996:76). This is an unusual situation, since most other situations of scarcity, called “relative” or “conditional” scarcity, occur when resources are at least potentially available but society does not consider it worthwhile to provide the resources to all those who seek them (Koch 1996:76).

From an anthropological perspective, kidney transplants could be seen as “relatively scarce” resources in two regards. Since ESRD is a cultural product of technological advances as shown in Chapter 3, we could say that only those cultures that have intentionally developed the technology to keep people with ESRD alive and have consequently established a disease category “ESRD,” experience the demand and scarcity of kidneys. Thus, scarcity is relative to culture. In another sense, as previously discussed, organ donation is largely a cultural matter. If we were to eliminate cultural barriers to organ donation, then there would be substantially more kidneys available for transplantation. This potential flexibility in kidney availability reflects a context of “relative” rather than “absolute” scarcity. The difference between bioethical and anthropological perspectives on classifying kidneys as scarce resources illustrates how bioethical distinctions are culturally bound.

Regardless of whether scarcity is classified as absolute or relative, a system of kidney allocation is necessary. It is unlikely that scarcity is entirely absolute given that culture is always

changing and events or processes e.g., accidents like the death of Nicholas Green in Italy<sup>37</sup> (*People Magazine*, October 4, 1994:64) or educational interventions, often effect a society's donation practices.

The issue of distributive justice is particularly resonant in the case of kidney patients because, unlike any other patient, all are entitled by Medicare to treatment by either dialysis or transplantation. Even in the face of entitlement, patterns have emerged showing distinct social biases in dialysis and transplant professionals' selection of patients for transplantation, as shown earlier in this chapter. An examination of the existing data indicates that injustices in access to kidney transplantation tend to occur less while actually waiting for a kidney after being placed on the waiting list, but more often during the process of seeking access to the waiting list (Kallich, et al., 1993; Childress 1991). Bioethicists, therefore, have emphasized the need to conduct research:

"to determine the extent to which unequal access to kidney transplantation, for example, hinges on patient choices and legitimate medical factors rather than on physician sequestration of patients in dialysis units, physician failure to inform and refer some groups of patients, or physician bias in the selection of patients seeking admission to waiting list" (Childress 1991:185).

Chapters 6-10 of this work examine how treatment decisions by clinicians and patients influence patients' access to transplantation.

The formal criterion bioethicists use to define justice is "similar treatment for similar cases" (Childress 1991:183-4). The second set of criteria bioethicists use are called material criteria or microallocation criteria. Microallocation of healthcare resources involves "decisions regarding particular persons" (Kilner 1995:1067). Microallocation or "patient selection" entails "determining which patients among those who need a particular scarce resource, such as a heart

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<sup>37</sup> Nicholas Green was a seven year old American boy who was shot to death by Italian bandits. His parents donated his organs to Italians in need. Prior to Nicholas' death, Italy had one of the lowest rates of organ donation in Western Europe (Land and Cohen 1992). That rate of organ donation increased by 400 percent in the days following Nicholas Green's death attests to the fact scarcity is relative to culture (*People Magazine*, October 4, 1994:64).

transplant, should receive treatment” (Kilner 1995:1067). In kidney transplantation, there are two facets of microallocation: patient selection for the waiting list and the distribution of kidneys to patients on the waiting list. Another facet of microallocation proposed in this research is the referral of patients to transplant centers. The microallocation debate for kidney transplantation thus concerns the moral relevance and weight applied to material criteria used in forming a waiting list and distributing organs to patients on the list.

Bioethicist John Kilner (1990, 1995) delineates the variety of material criteria within five categories: social, sociomedical, medical, personal, and impersonal. Let us briefly review each of the material criteria within these categories since their relevance to kidney transplantation is discussed in Chapter 10 (see Table 4.1). Criteria are social in that they “seek to promote some particular or general social good as a result of the allocation decisions made” (Kilner 1995:1076). Material criteria in this category include: social value (prioritizes those most likely to be valuable to society in the future); favored group (prioritizes people of a certain type e.g., veterans, children, or those who live in a certain geographic area); resources required (prioritizes those who need less of a given resource before those who need more of it); vital responsibilities (prioritizes patients on whom others depend); and progress of science (prioritizes patients whose treatment will yield the most scientifically useful information).

Criteria are sociomedical in that they seek to promote social good but their justifications are medical in nature. A key material criterion in this category is patient age in that priority is accorded to younger patients because they tend to benefit more than the elderly who are weakened by old age. Thus younger patients tend to have a greater likelihood of benefit, length of benefit, and quality of benefit than elderly patients. The second sociomedical material criterion is psychological ability, which prioritizes the ability of patients to cope emotionally and

intellectually with treatment since these qualities are assumed to be essential to effective health care, and without it, patients may be unable to follow instructions. Lastly, supportive environment favors patients with the most supportive living environment during and following treatment since this is believed to help prevent the waste of scarce resources.

Medical criteria explicitly relate to health-related outcomes of treatment. The first criterion is medical benefit, which prioritizes those with a reasonable likelihood of receiving a significant length and quality of medical benefit from treatment. This is rooted in ethical standards of efficiency and justice, since resources would otherwise be wasted on those who could not benefit from them. Medical urgency prioritizes those who will die soon without treatment. The last three criteria pertain to issues of medical effectiveness. These include: likelihood of benefit (which prioritizes patients with the greatest likelihood of medical benefit); length of benefit (which prioritizes patients with the greatest likelihood of living the longest following treatment); and quality of benefit (which prioritizes patients with the greatest likelihood of producing a high quality of life).

Personal criteria are justified on the basis of personal values such as liberty and the worth of the individual. These criteria include: willingness (prioritizes patients who genuinely want treatment); responsibility (steers resources away from people who engage in unhealthy lifestyles or risky activities that result in the need for treatments); and ability to pay (excludes people with insufficient funds from health care).

The last type of material criteria are impartial in that arbitrary methods of allocation are used. These criteria are used after the aforementioned types of criteria have been applied and there remain more eligible candidates than resources to provide. The rationale is that “each person who has an equal moral claim on a scarce resource should have an equal opportunity to

receive it” (Kilner 1995:1081). The two criteria are types of random selection, including first-come, first-served (prioritizes those who have been waiting the longest); and lottery (prioritizes those who, by blind chance, are selected for treatment).

**Table 4.1 Criteria of fairness in distributing scarce medical resources<sup>1</sup>**

Categories of Material Criteria	Sub-Types of Material Criteria				
Social	social value	avored group	resources required	special responsibility	progress of science
Sociomedical	age	psychosocial ability	supportive environment		
Medical	medical benefit	medical urgency	likelihood of benefit	length of benefit	quality of benefit
Personal	willingness	responsibility	ability to pay		
Impartial	lottery	first-come, first-served			

1. Based on Kilner (1990, 1995).

Notions of fairness in various bioethical contexts usually rely on one or more material principle of distributive justice (Beauchamp and Childress 1994:329). Material principles specify “relevant properties” that individuals must possess to qualify for a certain distribution (Beauchamp and Childress 1994:331). Relevant properties can be established by tradition, moral or legal principle, or by policy. In the US, scarce medical and other resources are often distributed according to a combination of different theories of distributive justice.

Bioethicists generally agree that there are four theories of justice which emphasize different material principles of distributive justice: libertarian, communitarian, egalitarian, and utilitarian (Beauchamp and Childress 1994:334). Libertarian theories of justice emphasize the social and economic rights to liberty (invoking fair procedures instead of outcomes of policies and procedures on individuals). The US has traditionally maintained a libertarian view of distributing health care through the marketplace, which is based on the material principle of ability to pay (Beauchamp and Childress 1994:336). In this theory, health care is not a right.

Communitarian theories focus on the “principles and practices of justice that evolve through traditions in a community” (Beauchamp and Childress 1994:334). In other words, the manner of distributing goods should be based on the values endorsed by each community. According to communitarian, Michael Walzer (1983), community traditions in the US have already developed interests in equal access to health care as a social good since public funds currently finance research and public hospitals.

Egalitarian theories of justice propose that individuals have equal access to goods such as health care (invoking material criteria of need and equality). An egalitarian health system would equally allocate a minimum amount of health care resources to people irrespective of wealth or position. Thus each person would have an equal opportunity to receive what is established as a basic or adequate level of care.

Utilitarian theories of justice concentrate on maximizing public welfare by invoking a mixture of material criteria. Utilitarianism is one form of consequence-based theory or consequentialism is:

“a label affixed to theories holding that actions are right or wrong according to the balance of their good and bad consequences. The right act in any circumstance is the one that produces the best overall result, as determined from an impersonal perspective that gives equal weight to the interests of each affected party” (Beauchamp and Childress 1994:47).

The principle of utilitarianism asserts that “we ought always to produce the maximal balance of positive value over disvalue (or the least possible disvalue, if only undesirable results can be achieved” (Beauchamp and Childress 1994:47). It is represented by the phrase, “The greatest good for the greatest number.” The US allocation system has been shown to be utilitarian, especially when policy makers are individualistic rather than community-oriented (Lindbladh, et al., 1998).



Notions of justice or fairness and of how to achieve it vary from culture to culture and throughout time. Social and cultural values determine, in part, the kinds of criteria people consider in decisions about resource allocation (Kilner 1990, 1984; Jecker and Berg 1992; Calabresi and Bobbitt 1978; Lowe, et al., 1995). In terms of the cultural basis of the concept of justice, Jecker and Berg (1992) point out that contemporary notions of justice assume three points. First, justice is believed to not be carried out through beneficence. That is, a just form of distribution entails giving to others because of right/entitlement rather than because of moral kindness and generosity toward persons in need. Second, justice demands impartiality, which implies equality, connotes public approval, and forbids privileging close relations. Third, justice is assumed to occur between strangers, meaning that decisions about resource allocation are made with little regard for relationships and responsibilities to others. Jecker and Berg (1992) show, however, that in practice, rural American primary care physicians make allocation decisions in ways counter to these assumptions. For example, the physicians made decisions about healthcare allocation: a) within a context of community relations in which social ties formed the basis of neighborliness, b) within competing loyalties: they sometimes turned away patients in order to support the viability of the hospital, and c) motivated by their sense of personal responsibility for patients by treating them on a case-by-case basis to fit patients' financial constraints. Evidently, the rural physicians' approach to justice is characterized by a collectivist rather than an individualist orientation. This relational world view in resource allocation is similarly apparent among the Akamba people of Kenya. This is manifested in the value of saving the lives of elder members of society before younger persons because "the older a person becomes the more intricately interwoven that person becomes in the lives of others and

the greater the damage done if that person is removed” (Kilner 1990, 1984). This finding, however, was based on a forced-choice hypothetical case.

In terms of dialysis, countries vary in their allocation criteria. In Italy, simple egalitarianism mandates that all who need dialysis are given equal chances to receive it. Why, Italians reasoned, should those with a shorter life expectancy receive lower priority than those whose expectancy is longer through no merit of their own? (Calabresi and Bobbitt 1978:182). By contrast, in England, the aged and the young are excluded from the pool of possible transplant recipients because the aged present greater medical risks, and because the young are less likely to adhere to a strict regimen thought necessary for successful dialysis (Calabresi and Bobbitt 1978). In Jamaica, where 45% of patients with ESRD were not offered maintenance dialysis because of inadequate facilities, significantly more patients on dialysis are under age 60 (Barton, et al., 1996). In contrast, most patients on dialysis in England, and in other developed countries, are over age 60 (Barton, et al., 1996; Chugh and Jha 1995). International variance in the values of justice and availability of resources (financial and donor organs) reflect the importance of cultural and historical contexts in shaping allocation practices.

In the case of kidney transplantation in the US, “[t]he fundamental ethical conflict in the distribution of scarce organs is between doing the most good with a scarce resource and ensuring that it is distributed fairly” (Brock 1988:87). With regard to the first objective, there are at least two competing values that can be seen as equally important: medical benefit and likelihood of benefit. According to the Department of Health and Human Services (DHHS) Task Force, “the prevailing ethos and practice are to allocate organs to the recipient who will live the longest with the highest quality of life” (Task Force on Organ Transplantation 1986).

The probability of success is important because it reflects medical utility -- which maximizes the welfare among patients suffering from ESRD. "Medical utility requires that organs be used as effectively and as efficiently as possible to benefit as many patients as possible" (Childress 1991:184). "Criteria of medical efficacy are frankly utilitarian because they aim to maximize the number of quality-adjusted life years saved in use of the donated organ" (Robertson 1989:3398). Regarding the second allocation objective, distributing kidneys to everyone regardless of outcome, would mean that some patients would derive little medical benefit, resulting in the waste of kidneys.

Bioethicists have asserted that the material criteria for selecting recipients for kidneys and allocating kidneys is "essentially value-laden" (Spicker 1992:141; Brock 1988; Childress 1991; Majeske 1996). Healthcare professionals believe that medical criteria are objective because they are ascertained by medical personnel using medical techniques and procedures. The "tendency to presume that medical criteria are *objective*" leads transplant professionals to believe that medical criteria are "reliable toward the end of fairly distributing scarce organs" (Spicker 1992:141). However, bioethicists posit that value judgments implicitly lie in transplant professionals' determination or weighting of factors leading to the greatest probability of medical success (Brock 1988:88). In other words, values and beliefs establish a strong basis for the choice of medical criteria selected for consideration, and then for the choice of one criterion to prioritize over others. For instance, the standards used to define medical efficacy reflect a normative or ethical judgment about the length of benefit or quality of life that kidney transplants should provide (Robertson 1989). A standard of 2-5 years of graft functioning post-transplantation implicitly deprives those patients of a transplant who might survive only a few months or who might survive longer but in a poor physical state.

Bioethicists and health care policy makers rely on putatively objective data to allocate scarce resources equitably (Majeske 1996). Majeske contends that the choice of objective data to consider in decisions of fairness is shaped by cultural values. She argues for a need to expand the definition of objectivity to include input by society. I argue that a utilitarian conception of fairness is a cultural tool in terms of its reliance on objectivity. In other words, fairness is obtained through reliance on what is considered objective. As we will see, one measure of objectivity is statistics. The US relies on statistics as a mechanism to make utilitarian policies function. As will be shown in Chapters 6 and 10, statistics are the mechanism for enacting utilitarian ideals.

### **Policy**

Policy can be defined as “the principles that govern action directed towards given ends” (Titmuss 1974:23 in Shore and Wright 1997:5). The analysis of policies and how people respond to them is relevant to this dissertation research because it is argued that cultural values are encoded in various dialysis and transplant policies. This includes policies on educating patients about their treatment options, referring patients, behaving ‘appropriately’ in the dialysis unit, and selecting patients for the kidney transplant waiting list.

An anthropological approach to policy analysis is used in this study because it views policies as cultural phenomena (Shore and Wright 1996, 1997).<sup>38</sup> As cultural texts and agents, policies codify social norms and values. In addition, drawing on Malinowsky’s notion and function of ‘myth,’ policies serve as a guide to behavior and charter for action (Shore and Wright 1997:7). Further, policies are political phenomena that articulate (implicitly) power relations

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<sup>38</sup> The anthropology of policy is a very recently established field in anthropology. The only book dedicated to this field as of yet is edited by Shore and Wright (1997). There are also several recent articles on anthropological studies of policy in a special issue of *Social Science and Medicine* (e.g., on abortion, HIV research, smoking) but these have not addressed policy as an anthropological field of inquiry as explicitly as Shore and Wright do (see Anglin 1997a,b; Lazarus 1997; Stebbins 1997; Waterston 1997; Whiteford and Vitucci 1997).

through discourse (see Waterston 1997; Stebbins 1997; Whiteford and Vitucci 1997; Lazarus 1997). Drawing on Foucault, Shore and Wright explain that “the masking of the political under the cloak of neutrality is a key feature of modern power” (1997:8). Further, “policy can serve to cloak subjective, ideological and arguably highly ‘irrational’ goals in the guise of rational, collective, universalizing objectives” (Shore and Wright 1997:11). Chapter 9 describes nephrologists’ referral practices in response to a federal policy while Chapter 10 examines how the transplant team evaluates patients according to both hospital and transplant center policies which encode sociocultural values.

There are two types of policies: *de facto* and *de jure*. Whereas *de facto* policies exist by virtue of informal adaptations to new conditions or traditional practices, *de jure* policies are written and legally established. This study argues that the form policies take (*de jure* or *de facto*) and how strictly people adhere to them are culturally-based decisions. Chapter 10 shows that the transplant team relies heavily on *de facto* policies in their patient evaluations and decision making perhaps because they cloak subjective values (e.g., personal responsibility) under putatively objective measures when dealing with moral uncertainty in the context of scarcity. The analysis of how dialysis and transplant professionals draw upon policies to make “fair” decisions is an example of the formal structure of health care, as noted in Chapter 1.

## **CHAPTER 5: EXPERIENCES OF DIALYSIS: ETHNOGRAPHIC VIEWS**

The last chapter reviewed the bioethical issues pertaining to problems with access to kidney transplantation. Before examining clinicians' and patients' decision-making process, it is first necessary to understand the context of their decisions and the nature of interactions between them occurring within those settings. As noted in Chapter 1, the context of clinical encounters affects communication between healthcare professionals and patients.

The purpose of this chapter is to introduce the clinical contexts of dialysis patients' lives that play a role in their treatment decisions. This includes a brief ethnographic description of the clinical sites in which dialysis patients are routinely provided care, the healthcare professionals who provide their care, and personal accounts of patients' experiences of dialysis and its effects on their lives.

Learning about these clinical contexts is important for several reasons. Generally speaking, it reveals some of the factors that patients' and clinicians' consider when making decisions about ESRD treatment. More specifically, patients' experiences of dialysis at the dialysis center largely inform their treatment decisions. Further, it is in these loci where clinicians learn about patients through interactions with them. The nature and extent of clinician-patient interactions subsequently effect clinicians' decisions about treating or referring patients.

The chapter is divided into four sections, each focuses on one clinical site. The clinical sites include: a) the nephrology clinics, where patients meet with their nephrologists for routine visits, b) the transplant center, where patients are evaluated for a transplant by transplant professionals, and c) the dialysis center, where patients receive renal replacement therapy three times a week. The first three sections describe two issues: a) the healthcare professionals found

at the clinical site, and b) the setting and nature of the healthcare professionals' activities there. The fourth section of the chapter presents an account of patients' experiences on dialysis and being at the dialysis center, the effects of dialysis on their lives, and a brief picture of physicians' perceptions of patients' experiences with ESRD.

## NEPHROLOGISTS AND THE NEPHROLOGY CLINICS

This section introduces nephrologists, who they are, and the nature of their work. It also presents a general description of the clinic's setting and the nature of routine interactions there between patients and their nephrologists.

### **Who are Nephrologists?**

Nephrologists are renal specialists, also known as 'kidney doctors,' who monitor patients' kidney function, and related medical conditions (comorbidities), such as hypertension and diabetes. There are two kinds of nephrologists: dialysis and transplant nephrologists. Dialysis nephrologists are solely concerned with managing the health of dialysis patients. Transplant nephrologists are concerned with managing the care of both dialysis patients and patients who are preparing for or who have already had a kidney transplant. In addition, transplant nephrologists are involved in evaluating whether ESRD patients are suitable for undergoing a kidney transplant by considering patients' renal and comorbid clinical conditions. Both types of nephrologists at AH are responsible for meeting with their patients in clinic visits. The frequency of visits increases as a patient's renal disease progresses toward renal failure; on average they meet once every 3 to 6 months for patients whose renal disease is not yet end-stage, and once a month for ESRD patients.

## **The Nature of Nephrology Work**

Nephrologists monitor renal disease patients by evaluating and comparing past to present chemical laboratory values. They modify patients' biochemical parameters to obtain chemical balance. Monthly summaries of patients' laboratory test results (e.g., blood pressure, creatinine, blood urea nitrogen levels) are sent from their dialysis center to their nephrologist for review.<sup>39</sup> The nephrology clinic is located in one wing of AH, next to other internal medicine clinics. At the nephrology clinic, each AH nephrologist is assigned two or three clinic rooms to use, one of which serves as a temporary office. While finishing the clinical visit with one patient, the next patient is brought by a nurse from the waiting room to another clinic room to await the nephrologist; this seemed to maintain efficiency in the physicians' schedules. There is a physician's lounge located in the rear of the clinic where nephrologists can retrieve up-to-date patient information on two hospital computers, and return urgent pages on the hospital telephones. The average number of patients seen in an afternoon was about four or five. Each clinic visit lasted approximately fifteen minutes, except when the new patient is new, in which case the visit lasted thirty minutes to conduct a full medical history.

As an academic hospital, fellows, residents and medical students sometimes join nephrologists in their clinical encounters with patients. On those occasions, the nephrologist and resident reviews the patient's medical history in the hallway or in the lounge before entering the patient's room to become organized and establish a plan before seeing a patient. Upon entering the room, the nephrologist introduces the resident (and myself), indicating that the resident is going to conduct the medical history, and that the nephrologist is going to leave in the meantime

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<sup>39</sup> One nephrologist indicated that nephrologists are alike in personality because they have to be highly detail oriented about many 'lab' values and revise prescriptions of different medicines to control for fluctuating laboratory results.



but will return later on. While the resident conducts the medical history, the nephrologist is busy beginning the clinical encounter with another patient. After completing the medical history, the physicians reunite in the lounge (sometimes it took several minutes for the nephrologist to rejoin the resident), to discuss the resident's care plan for the patient. Their discussions focused on interpreting the recent laboratory tests in light of the patient's medical history. After the nephrologist guides the resident to establish a plan of action, they both return to the patient to conclude the encounter.

### **A Clinic Visit in the Life of a Nephrologist**

Here is a depiction of a typical clinic visit, it is a composite picture generated from observations made during many such occasions. Clinic visits involve several stages. The first part is the initial encounter. The patient (and often a family member) is already present in the office when the nephrologist enters. Upon entering, the nephrologist greets the patient and sits at the small desk which faces a wall. Many nephrologists half-turn to speak with the patient, who is seated in a chair to the physician's right. The doctor proceeds to ask how the patient is doing, if the patient is experiencing any symptoms of nausea, headaches, dizziness, fatigue, etc.

The second stage begins with a review of the patient's medications. Patients are asked to bring their medicine bottles with them so that the nephrologist can verify the names and doses (and double check to see whether the medicines are being taken) in the patient's medical record. The nephrologist also asks patients about changes in medications newly prescribed and recently dropped by the patient's primary care physician. During this time the nephrologist writes the updated information in the patient's medical chart. Next, the nephrologist asks a series of questions about the patient's health, appetite, diet, potential problems, e.g., 'Do you have

problems with nausea, vomiting, appetite?’ The purpose of asking these questions of pre-dialysis patients is to determine whether their renal failure is progressing.

The third phase involves the physical exam. The nephrologist asks the patient to sit atop the examination table. The doctor takes the patient’s blood pressure, listens to the patient’s heart, lungs, conducts an eye exam, and tests for edema (swelling caused by fluid overload) by pressing on the patient’s ankles and legs.<sup>40</sup>

When the physician asks the patient to return to the chair, the last phase of the clinical encounter begins. At this point the nephrologist presents the patient with new diagnostic and prognostic information as well as the plan of action. They may cursorily educate patients about different treatment options for ESRD. Sometimes the education process occurs in the first phase of the visit if patients had just attended the pre-dialysis class, and nephrologists ask about patients’ treatment decisions. At this point, the nephrologist may tell patients to make lifestyle changes (e.g., to change their diet, exercise, stop smoking) that help delay the onset of ESRD or comorbidities, or to go to the pre-dialysis education class. The nephrologist may also ask patients if they are interested in kidney transplantation and hand them the transplant center telephone number. The clinic visit concludes with the nephrologist asking the patient if he or she has any questions, and if not, the visit ends, and the nephrologist leaves the room.

### TRANSPLANT PROFESSIONALS AND THE TRANSPLANT CENTER

This section describes the transplant professionals involved in evaluating patients for a kidney transplant and their role in the evaluation process. Unlike the other sections of this

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<sup>40</sup> As part of their training and experience, nephrologists have the uncanny ability to remember the minute shifts in fluid buildup in each patient’s ankles over months.

chapter, this one begins by describing the setting of the transplant center in which transplant professionals work.

### **The Transplant Center**

The transplant center at AH is one of eleven transplant centers in this state as of 1995 (HCFA 1997). AH is a midsize, non-profit transplant center, and currently performs only kidney, kidney-pancreas, and liver transplants. The program is expanding to include heart transplants in the near future. It began conducting kidney transplants in 1969, and has performed a total of 1,121 kidney transplants as of July 1997 (Katz 1997). The AH transplant center maintains what an outsider might call a ‘liberal philosophy’ in that all patients should be given a chance to get a transplant. As one transplant coordinator, Kathy, explained, “everybody should have the opportunity to be given a chance to receive an organ.” This philosophy translates into taking on more difficult cases that other transplant centers turn down, notably patients with cardiac problems.

Ideally, patients have a choice of which transplant center to attend. However, several external factors influence which transplant center patients ultimately go to for their care. These factors -- usually beyond patients’ control -- are important issues because they can influence patients’ treatment decisions, as will be discussed in further detail in Chapters 6-8. Usually patients are directed to a certain transplant center because their insurance carrier decides for them. Insurance companies establish contracts with transplant centers based on the one year kidney graft and recipient survival statistics. Without good statistics and insurance contracts, transplant centers cannot afford to run. Patients who prefer to go to a transplant center that is outside of their insurance’s “network” must pay for the costs that the insurance does not cover. In such cases, the AH head transplant surgeon, Dr. Benton reported that he asks the insurance

company to make an exception for the patient. The insurance company will either deny the request, or will work out a payment plan, which entails paying a smaller percentage than usual, and the patient to cover the rest. But Dr. Benton claims he has never made patients pay out-of-pocket. He accepts the amount the insurance gives him. He believes that the extra \$1,000 that he would receive from a patient out-of-pocket would make little difference to his or to the program's income, and it would probably be a "hardship" on the patient to come up with that money. It is unknown whether other transplant centers follow suit.

Patients may also chose one transplant center over another based on where their nephrologist is employed, research into the transplant center's size and survival statistics<sup>41</sup>, proximity to their home, and personal impressions of the transplant center. Several patients in this study reported that they had begun the evaluation process at the CMC, a for-profit transplant center, but then transferred their care to AH because they were dissatisfied with the care they had received. According to a AH transplant surgeon, about 10-15 patients transfer from CMC to AH a year. The transplant professionals at AH have a reputation for being more "caring" and interpersonally helpful than those at the other transplant center in the area.

#### **Patients' Interactions with the Transplant Team**

Once patients have been referred to the AH transplant center they go through a three month evaluation process by an interdisciplinary transplant team before they can be considered eligible for wait-listing.

The transplant team is composed of the following healthcare professionals, all specialists in the area of transplantation in the following fields: surgeons, nephrologists, coordinators (clinical nurse specialists), social workers, and a medical secretary. The evaluation process

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<sup>41</sup> A transplant center's size or volume of patients transplanted per year is intricately related to its survival statistics; generally, the larger the volume, the better the survival statistics.

entails undergoing, in the following order, medical exams by physicians, educational sessions about transplantation, and laboratory tests. The course of evaluation takes about six weeks because the laboratory tests take several weeks to process after they have been conducted.

Patients begin the process by meeting with the transplant surgeon and then with the transplant nephrologist (often scheduled on the same day) for a medical exam and assessment of the clinical feasibility of the patient undergoing a kidney transplant. On another day, the patient then meets with the rest of the team, including: a transplant coordinator (clinical nurse specialist), a transplant social worker, and then the medical secretary in half-hour back-to-back educational sessions for further clinical evaluations. Patients usually only meet with transplant professionals once during this evaluation process.<sup>42</sup> Each of these meetings between patients and transplant professionals is described below.

#### Transplant surgeon

The transplant surgeon is responsible for assessing whether or not a patient is physically capable of undergoing the two and a half hour kidney transplant surgery considering a patient's cardiac status, age, weight, and body size and shape. The surgeon makes this assessment after meeting with the patient and considering the comments made by other transplant professionals. The meeting between the transplant surgeon and patient involves taking a brief medical history and informing patients of the risks and benefits of transplantation. The surgeon reviews the patient's history of cardiac problems and drug use, including alcohol, and smoking. The surgeon provides a full five minutes worth of data and statistics about the survival rates of cadaver versus living related kidney donations, and the likelihood of rejection or other side-effects occurring,

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<sup>42</sup> The exception is when marginal patients are reviewed at the selection meeting and required to meet with transplant professionals and undergo further clinical tests to make a better clinical judgment about the patients' suitability for transplantation.

e.g., lymphoma, skin cancer, rejection. This meeting is also a way for the two parties to become acquainted and informed. The vast majority<sup>43</sup> of the patients seeking a kidney transplant are deemed eligible by the surgeon for a transplant and are automatically wait-listed after their evaluations with other members of the transplant team are completed; they do not go before the team for further evaluation at the monthly meetings.

The meetings with transplant nephrologists are essentially those described in Chapter 6, however, like the surgeon-patient clinics, additional clinical information regarding the risks and benefits of transplantation is presented.

#### Transplant coordinator

The transplant coordinator (clinical nurse specialist) has a variety of responsibilities including: educating potential kidney recipients, calling patients in for a transplant, outpatient care of transplant recipients, making decisions about medications, helping patients with personal, social, and medical problems, and data collection. Unlike some other transplant centers, each transplant coordinator at AH follows a set of patients before and after the transplant to maintain continuity of care. During the educational sessions, transplant coordinators inform patients about the risks and benefits of transplantation, surgery, the recovery time, the medications, the length and type of side-effects of medications, how kidneys are matched and allocated, and the possibility of obtaining kidneys from living-donors. Transplant coordinators contribute to the patient evaluation process by giving their opinions to the rest of the transplant team about patients who showed warning signs of future problems.

One major warning sign is patient noncompliance, and as will be discussed in Chapter 10, the concern about noncompliance factors into transplant teams' evaluations of potential

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<sup>43</sup> The transplant center did not track marginal patients who were not wait listed.

recipients. For example, one transplant coordinator, Kathy, noted that she communicates her opinion of patients who say things like ‘I don’t always take my medicines,’ ‘I sometimes skip a dose,’ or ‘I don’t always go to dialysis, sometimes it depends on how I feel about whether or not I go to dialysis’ because, Kathy noted, these statements show that “people basically admit that they’re not doing what they know they should be doing” which can affect graft survival.

#### Transplant social worker

The transplant social worker is responsible for identifying how patients will “participate in living as a transplant recipient” by assessing their psychological and social background. This includes evaluating patients’ financial resources, social supports, compliance behavior, and other factors including alcohol and drug use, and psychological problems since these issues may present problems with patients’ maintenance of health post-transplant. In addition, social workers determine whether patients can understand instructions, or have transportation back and forth to the hospital. Social workers also help patients to obtain medications and to adjust to living with a transplant. This means helping patients become rehabilitated by informing them about strategies for seeking employment or further education.

Social workers help patients plan and manage the costs of medications post-transplantation. Social workers meet with and educate patients in two different contexts: during the information session and during annual reorientation meetings. During the educational meeting the social worker helps patients set up a plan to cover the costs of medicines, and provides information about the extent of aid they can expect from their insurance companies. Transplant social workers reported that they are increasingly stressing the need for patients to focus on financial planning early on because of decreasing amounts of financial support available

from pharmaceutical companies and nonprofit organizations to help patients cover the costs of medications.

Patients on the waiting list are required by the transplant center to attend an annual reorientation meeting to inform and refresh patients about insurance issues and medications, and to offer patients an opportunity to ask questions. Led by a AH transplant coordinator and a transplant social worker, these classes last about an hour and a half. The social worker reviews the insurance policies and any changes that have occurred. During these meetings, the social worker strongly encourages patients to be aware of their insurance's coverage policy. For instance, one social worker told the group of patients one night:

"Resources are getting tighter, make sure you're aware of the issue. I need for you to think about it you have private insurance with prescription privileges. You need to know the rule of use. Be externally vigilant of the changes in your health plan, the rules and regulations for your prescription coverage, and whether it's an annual or lifetime max. We will work with you at the time of transplant to keep costs at a minimum."

#### Medical secretary

The medical secretary is responsible for conducting intake interviews over the telephone with referred patients who wish to be evaluated for a transplant. This entails eliciting information from the patient about their demographic background, medical history, and dialysis regimen. The secretary schedules all appointments with the transplant team. It usually takes about 3-4 weeks between the patient's initial call to the transplant center and their first appointment with the transplant team.

The remainder of the evaluation process involves patients undergoing a battery of clinical and laboratory tests to determine whether there are any clinical contraindications to undergoing the transplant surgery. These tests also vary depending on the patient's clinical condition. See Table 5.1.



**Table 5.1 Transplant work-up requirements<sup>1</sup>**

Patient Condition	Laboratory tests required or conditions met
All patients	Tissue typing, chest x-ray, EKG, visit dentist
Polycystic kidney disease	Abdominal CT scans
Diabetic	Vessels, cardiac, vascular studies
Pancreatitis	Patient is insulin dependent
Lupus	Lupus is quiescent
Enlarged heart	Echocardiogram
Aged over 50	Cardiac evaluation
Aged over 60	Vascular studies, ultrasound to ensure iliac vessels not calcified
Male	No prostate problems exist
Female	Gynecology, pap smear, mammogram studies

1. Based on interviews with transplant professionals.

### DIALYSIS PROFESSIONALS AND THE DIALYSIS CENTER

This section of the chapter describes who dialysis professionals are and the setting of dialysis centers in this study. This section focuses on describing the dialysis professionals, the demographic background of people in the dialysis centers included in this study, the organization within dialysis centers, and concludes by describing a typical routine at a dialysis center. Because the setting of dialysis treatment and patients' experiences of it inform their treatment decisions, it is necessary to present this contextual information before examining patients' actual treatment decisions in Chapter 7.

#### Dialysis Professionals

Dialysis centers employ a variety of staff: nurses, technicians (called "techs"), dietitians, social workers, art and music therapists, and administrators. The number of each type of employee and the patient-staff ratio vary by the size of the facility. Nurses and technicians do the work of initiating and removing patients from dialysis treatment (hooking up and disconnecting them from the machine), monitoring their blood pressure and other physiological measures, and keeping a watchful eye on them during the treatment to ensure that problems do not occur (e.g., seizures, vomiting, needles popping out). Nurses also have administrative duties, e.g., organizing the schedule of patients. Social workers interview each patient at the onset of dialysis

for an initial psychosocial evaluation. They also provide, on an ongoing basis, individual counseling, assistance with Medicare, state applications, and other support with transportation, food stamps, job rehabilitation services, etc. Nurses and social workers are also responsible for educating patients about their treatment options. Dietitians advise patients about their diet and ways of preparing their food. Staff members are easily identifiable because they must wear white coats and protective eye wear because of their close contact with blood products.

The dialysis centers were located directly in Cleveland and in its various suburbs. All of the dialysis centers shared similar features (e.g., the staff employed there, staff-patient interactions, the scheduling of patients for treatment, etc.). The following description is based primarily on the NDC closest to AH, because the vast majority of time interviewing patients took place there. This was because most of the AH patients attended this center due to its central location in the inner city; it was located within a 10 minute walking distance of AH. It was the largest dialysis center in the country, with a patient population of over 375 patients.<sup>44</sup> For demographic data on each dialysis center in this study, see Table 5.2.

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<sup>44</sup> The number of patients at dialysis centers fluctuates because many patients are transferred to other dialysis centers, new patients come, some die, and some get transplanted. During the course of fieldwork, a new NDC opened up and over 30 patients from NDC 1 transferred to it.

**Table 5.2     Dialysis centers demographics<sup>1</sup>**

Facility	Status	# Stations <sup>2</sup>	Primary Payer: Medicare	Primary Payer: Medicaid	Primary Payer: Other	# % Black Patients	# % White Patients	# % Other Patients	Total Patients
AH <sup>3</sup>	non-profit	16 <sup>*</sup>	N/A	N/A	N/A	67 62%	40 37%	1 1%	108
NDC 1	non-profit	80	74%	15%	11%	362 94%	24 6%	0	386
NDC 2	profit	20	69%	5%	18%	53 41%	74 58%	1 1%	128
NDC 3	non-profit	16	74%	5%	21%	10 8%	110 91%	2 1%	122
NDC 4	profit	45	70%	6%	24%	183 86%	30 14%	0	213
NDC 5	profit	28	80%	2%	18%	60 45%	70 53%	2 2%	132
CH <sup>4</sup>	profit	24	N/A	N/A	N/A	N/A	N/A	N/A	110

1. Based on data from corporate headquarters of NDCs as of 2-20-98.

2. A station is an individual chair or bed for each patient to use during dialysis treatment.

3. Based on data provided by the center's Head Nurse as of 6/30/97.

4. Based on a pamphlet from the dialysis center and interviews with nurses.

\* Based on The Renal Network, Inc. 1996 Statistical Report for End-Stage Renal Disease Networks 9 & 10.

Patients chose which dialysis center to attend according to its proximity to their residence. Usually, new ESRD patients initially attended the AH dialysis unit until they became medically stable, and thereafter were transferred to the satellite or affiliated centers (NDCs). Some stable patients were allowed to remain at the hospital unit to fill open chairs. Patients could transfer to other dialysis centers if they moved residences or preferred to change, though it depended in part on whether centers had any openings in the patient schedule.

### **Structural Organization of Dialysis Centers**

Dialysis centers are divided into units, which are separate or adjoining rooms divided by semi-walls or none at all. Located within each unit are the stations or patient chairs and dialysis machines; stations are arranged around the periphery of the room, looking inward.<sup>45</sup> On average, there were approximately twelve stations per unit. In the center of the units were nursing

<sup>45</sup> Foucault shows how in the eighteenth and nineteenth centuries, the inner space of the asylum, hospital, and prison was architecturally designed in such a way that developed a relationship between subject and object. By situating patients or inmates in space around a core area of those in power -- via the "panopticon" -- staff can view patients or inmates as an object of knowledge and a subject of discipline (Foucault 1977; 1977).

stations, large tabletop areas where technicians and nurses worked or sat during their downtime, patients' medical charts could be read and written in, and a schedule of patients' dialysis shifts. In some centers sinks for draining old dialysate were located against one wall and in others they were located in the central area. Rolling chairs for staff were also stationed in the center area. Rolling carts also filled the room. Each multitiered cart contained various bottles of medicine (e.g., heparin to prevent blood clots), needles, and gauze pads used to hold down and clot the access site upon treatment completion.

Units are the locus of multiple senses: sights, sounds, smells, by all who enter the room. Units have a sterile feel to them in that only one side of the room has windows to allow in natural light, so artificial lights are usually on. In addition, the floor is linoleum, and the ventilation constantly blows cold air. The most distinctive feature is the pervasive smell of formaldehyde and other chemicals (used to clean artificial kidneys between dialysis treatments) throughout the dialysis center. The sights can be overwhelming: blood flows through clear tubes outside of each patient's body, patients arrive in wheelchairs and even stretchers, many have amputated limbs, some are sick, others cough up sputum, and most seem generally uncomfortable. In addition, units can become quite noisy from the perpetual beeps and blips of the dialysis machines, communication over the intercom, myriad television sets, and conversations between and among staff and patients. The atmosphere of the units changes over the course of the day: during daytime hours the staff work in a busy and rushed mode, while at night, with fewer patients, there is a more calm and relaxed ambiance in the facility.

In addition to units, dialysis centers have a waiting room, where patients wait to be called to begin their dialysis treatment. In this room stands an ice-machine which patients use to fill their cups with ice chips before going to their unit, and NDC quarterly newsletters that provide

an informal account of the past, present, and future happenings at the NDCs. A telephone-intercom system between all units and the waiting room facilitates communication between staff and patients. There are also specialized rooms that store and cleanse each patients' artificial kidneys, as well as serve as conference rooms and private offices. The halls are decorated with the artwork made by patients as well as seasonal ornaments. Some dialysis centers are newer than others and have new colorful carpeting in the hallways.

The atmosphere of dialysis centers appears on the surface level to be friendly and jovial. Many staff and patients share the feeling that they are like a giant family since they spend much time together and get to know each other. Staff joke with each other and with patients. For example, to foster feelings of good will among patients, the head nurse in charge of NDC 1 makes rounds daily through each of the eight units to personally greet each of the patients. Patients have little privacy since their chairs face all other patients. There are television sets and earphones attached to each chair for personal use. In addition, patients personalize their chair area by orienting the chair in an upright, relaxed or fully laid-back position, and by arranging personal articles they brought with them to occupy their time on the shelf attached to the chair: hard candy or snacks, books, personalized stereos, cordless telephones.

### **The Process of Setting-up Dialysis**

An example of the usual routine of setting up a patient to initiate dialysis treatment begins when patients arrive and check in with the receptionist in the waiting room. The receptionist then notifies the technician of his or her patient's arrival over the intercom. Before the technician asks the patient to enter the unit, the technician must prepare the patient's chair. This entails wiping down the chair with an astringent soaked cloth to sanitize it from blood particles left from the previous patient. The technician then drapes a clean sheet over the entire chair, ensuring it is

evenly covered, and places one or two folded blankets on the arm of the chair. Placed atop of the blanket is a sterile packet containing prepared syringes, needles, gauze, etc.

Upon entering the unit, patients weigh themselves on a large scale and then sit in their chair. Prior to placing the needles in the patient's arm and hooking the tubing up to the machine, technicians are required to have another technician double check that the artificial kidney attached to the machine is the correct one by reading out the patient's identification number written on it. Technicians will also hold up two vials of fluid obtained from the cleaned artificial kidney for patients to verify that neither contains signs of formaldehyde, which would be harmful if introduced.<sup>46</sup> The entire process of getting a patient hooked up to the machine takes about ten minutes.

## **PATIENTS' EXPERIENCES OF DIALYSIS AND ESRD**

This section of the chapter concentrates on the range of patients' experiences of dialysis, and then concludes by delineating physicians' perceptions of ESRD patients' experiences on dialysis. We can gain insight into patients' experiences of dialysis by examining how they felt about dialysis as a treatment, being at the dialysis center, how ESRD has affected their lives, and ways patients have learned to adapt to it. Patients' experiences of dialysis are important to understand because they influence treatment decisions. For a list of patients' pseudonyms by treatment choice see Appendix VI.

### **Experience of the Dialysis Center/Unit**

Dialysis facilities have tried to make the process of dialysis as tolerable and enjoyable as possible, by provisioning each station with an individual movable television. Many patients

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<sup>46</sup> This practice was initiated because patients have died from mishaps in the past.

reported enjoying watching TV. Yet patients found some environmental conditions of the dialysis units to be uncomfortable. For instance, patients perceived the temperature in the units as very cold and usually required two blankets.<sup>47</sup> In contrast, the heated air in the winter caused patients much itching.

Patients expressed similar feelings about doing dialysis. These views ranged from positive to neutral to negative feelings. With regard to positive views about dialysis, several patients (n=6) recognized its usefulness in keeping them alive. For instance, patients stated the following:

Anthony: "[dialysis] got me back to living."

Raymond: "[I] feel lucky that they have it."

Allison: "[Dialysis is part of my] normal life because I'm used to it... It saved my life... I thank God someone thought up the idea!"

Other patients reported enjoying the social aspect of dialysis. Dialysis has been described by medical sociologists as a 'home away from home' because it provides social interaction that many patients would not ordinarily receive without it (Gallagher 1994:86). Dialysis offers patients an opportunity to socialize with other people. Some take advantage of the situation they are in and make friends. As Donna, an unemployed woman noted, "It's like an outing, seeing people. I don't mind coming. If it wasn't for dialysis I wouldn't have anything to do." Another patient, Malcolm, bemoaned the changes within the facility that resulted in less social interaction. Regarding the change from sharing one TV with five people to everyone having their own, Malcolm said that consequently, "people are not as friendly as the last place. People don't

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<sup>47</sup> The President of the AAKD explained (5-25-98) on the Dialysis Listserv that the perception of unit temperature differs among people, particularly between staff and patients. On the one hand, staff tend to feel warm since they are constantly moving around (and wear a lab coat). On the other hand, patients feel cold because dialysis treatment involves a shift in fluids and electrolytes and a temporary loss of blood in the context of idleness.

interrelate anymore... people don't speak hello or good-bye because they have their earphones on and are engrossed in the TV."

In terms of neutral experiences of dialysis, at least four patients reported that they considered dialysis a job. As Shirley stated, "It's like a job that I have to do." Like having a 9 to 5 position, patients wished to forget about it when they went home afterwards. Common negative sentiments patients expressed about dialysis were of hate and resignation. In a sarcastic and biting tone Gina quipped: "I love it! How do you think I feel? I can't stand it, but know it keeps me alive." Most patients felt that they had no choice about whether or not to do dialysis since it is their lifeline. For example, Paige stated, "It's just a part of life. You do it or you die. You have no choice." While these comments above briefly depict the range of perspectives, below we can understand more in-depth patients' positive and negative experiences of dialysis in light of patient-staff interactions.

### **Dialysis Patient-Staff Relationships and Interactions**

This section presents three perspectives about patient-staff interactions: there are patients who experience a positive attitude about their relationship with dialysis staff; there are patients who experience an antagonistic relationship with staff; and there is the point of view of the clinical establishment and stipulated policies. Most of this section concentrates on the issues generating antagonistic feelings among patients toward staff because they best reveal the culture of the dialysis unit. A significant aspect of this culture is the medical establishment's concern over patient noncompliance, the implications of which are presented in Chapters 9 and 10. The culture of the unit can be interpreted in light of power dynamics. This dynamic will be explored further after reviewing patients' positive relationships with dialysis staff.



Most of the patients reported that they liked their technicians and nurses and had positive things to say about them. Some patients and staff even had a joking-relationship in which they teased each other for fun. Patients appreciated the staff's care-taking role, professional attitude, and the social interaction it involved. Statements to this effect include:

Malcolm: "I kind of like coming in and seeing these people. I get to rest and fall asleep because I know they're watching over me."

Tammy liked the staff and "the care they give you." She appreciated how their attitude is not 'this is my job' but rather "it's coming from the inside of them," they are "dedicated" and they work "not for a paycheck" and "I know when they're tired." She likes being closely monitored by the dietitian and getting her monthly report card. She also likes how "a bunch of people are working together for my benefit."

Clifford: "They treat me fine here... they look out for me, anytime I have problems."

In their research on dialysis patients' quality of life,<sup>48</sup> sociologists have found that patients and staff develop considerable rapport over time (Gallagher 1994; Klenow 1979; Kutner 1987). Factors contributing to the 'family' atmosphere include: 1) the physical structure of units maintains close contact, 2) the nature of the routine facilitates much interaction, 3) the serious quality of the illness and its treatment generate personalized interactions, and 4) long term contact brings familiarity with the patients' personal life and physiological reactions to dialysis (Klenow 1979:700). One patient commented on the factors that lead her to feel like the staff were part of her family:

Chantal: "If you see people as much as you do, you become part of a family. You get to know them [patients and staff], hear about their kids and family, have to build trust, understand that they [the staff] have your interests at heart, it's reciprocal... [It's a] job for them and a profession they've really chosen... [Without them] I would probably die if they didn't do their job."

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<sup>48</sup> Although "quality of life" is not the guiding question of this study, it is important to note that quality of life is currently a big issue of concern. There is a certainly large literature on quality of life issues comparing dialysis and transplantation (see Evans, et al., 1985; Kutner, et al., 1986; Koch and Muthny 1990; Simmons and Abress 1990; Kaplan De Nour 1994; Kutner and Brogan 1994), and on various other medical conditions. In addition, there is substantial debate centered on operationalizing quality of life (see Joralemon and Fujinaga 1996). I make reference to quality of life in an emic way, namely, as it is discussed by dialysis and transplant professionals and patients about patients' experiences of dialysis, and how it pertains to treatment decision making. This study is not an analysis of patients' quality of life per se, but only incorporates this issue into analysis as study respondents and relevant literature discuss it.

The extent to which patients and staff develop friendships is in part related to the staff-patient ratio. This ratio differed among dialysis facilities. In smaller units with fewer patients per staff member, relationships are more likely to flourish. One patient, Douglas, bemoaned his change from a small unit to a large unit: he described the small unit as “tight-knit” and “individual” since “it is not like the fifteen people here but more like ten [and the] techs are always there, more personal, and here it is not as personal because the techs have four other patients to care for.” A related factor influencing the development of friendships between patients and staff was the rotation of staff within the facility. Two patients (Pauline, Jerome) expressed dislike of the high rotation of staff. They reported how having different technicians each day or week made it difficult to get used to one style of needle insertion and to establish rapport with staff (see Kutner 1987).

In contrast to the positive relationships depicted above, there is also an undercurrent of tension between patients and staff. Medical sociologists have relatively recently recognized that conflicts between patients and staff arise about daily dialysis activities, e.g., the procedure for arriving late (Gallagher 1994). On the one hand, dialysis nurses in my study and others (e.g., Bestley and Watson 1993) contend that patients play “control games,” such as coming in late for treatment or not showing up for dialysis without calling, which makes some nurses angry. On the other hand, some patients perceive the dialysis staff as exerting dominion over them because patients are in a vulnerable position of being seated and tied down to a machine for hours on end, dependent on staff for assistance.

Most of the documented evidence supports the patients’ perspective. Patients have expressed their awareness of the staff’s potential power to inflict pain by harsh needle insertion (Kutner 1987). Dialysis staff have been shown to exert control over patients who fail to conform

to their expectations about taking initiative in their dialysis treatment (Alexander 1982). There is also evidence that tensions develop between patients and staff when patients present problems constituting a threat to the staff's medical authority, e.g., presenting diagnoses of uncertain medical problems (Plough 1981).

While studies document the existence of such tensions, they do not examine how each party engages in them. Thus we are left asking, How do these tensions play out? How do patients react to staff who appear to control them? How do staff react to patients who attempt to threaten their authority? We can approach these questions through a theoretical framework on power relations, which refers to "who has the authority to sanction the patient" (Hershel 1992:309).

According to Michel Foucault, power is discourse imposed by persons in authority and reinforced by established law (*in passim*, 1978:6). Foucault also considers power to be diffuse in that it does not rest in individuals or groups, and it is exerted in only one direction from the top down. People can be caught in complex webs of power relationships (Rhodes 1991, 1992). However, Rhodes (1991, 1992) argues that power flows in many directions, not one, and is wielded by all people in the action though in differing levels. For instance, in the case of an emergency psychiatric unit, hospital staff must account for the management of the medical condition of resistant patients to their supervisor-administrators (Rhodes 1991).

Key to our discussion here is Michel Foucault's observation that "where there is power there is resistance" especially in the space of social institutions (Foucault 1978:95). In the case of dialysis, those in authority appear to be the staff, since they have medical expertise about dialysis and ESRD. Furthermore, the staff have the ability to control access to dialysis machines via scheduling treatment times, control the functioning of the machine, and enforce sanctions for

improper behavior according to dialysis center policies. Yet patients have the capacity to file an official complaint about an offensive dialysis staff member to the facility administrators or even to the state dialysis network which is responsible for ensuring quality of care. Patients engage in forms of covert resistance, commonly used by those typically without authority to effect change, e.g., peasants (Scott 1985). Below we examine first the intentional and inadvertent mechanisms employed by dialysis staff to maintain control over patients, and then present ways in which patients engage in resistance against the staff's forms of power.

Dialysis staff have several means of exerting their power over patients, including structural and informal modes, and policy. The structural mode of exerting power refers to everyday medical practices relating to dialysis treatment. Informal modes of exerting power involve mechanisms of social control, e.g., gossip, fear, reputation management. Dialysis facility policies require patients to behave in certain ways. The analysis of the relation between policy and power will be examined last in light of patients' resistance.

A structural form of the staff's and dialysis facility's power over patients is illustrated well with the use of the dietary "report card." The meaning of the report card will become apparent after considering further Foucault's insight on medical practice. Just as other institutions (e.g., an asylum) can be seen as an embodiment of restraint (Foucault 1973, 1977), the institution of dialysis imposes restraints on the patient's body in the form of dietary limitations, among others. Dietary limitations appear to be the locus of much resistance by patients, and interpreted (sometimes pejoratively) by clinicians as noncompliance. Each month blood is drawn to conduct tests on patients' blood chemistries (e.g., phosphorous, potassium, calcium levels). The results of these tests are maintained in each patient's chart. In light of Foucault's analysis of the patients' dossier or medical charts, Rhodes writes, "the chart is

important to the disciplining of individuals because it makes them uniformly visible, organizing them in terms of standardized norms” (Rhodes 1991:110).

Dialysis clinicians review the degree of patients’ stability or ‘deviance’ reflected by their history of laboratory results to determine how closely patients have conformed to the idealized blood chemistries. When patients’ laboratory results show high instability or fluctuations, staff consider patients responsible for the anomaly, particularly through dietary and medication noncompliance.

To enhance patient conformity to standardized chemistries dietitians present patients with their monthly “report card” that lists their recent ‘scores’ on their chemistries. Reviewing the report card thus serves two purposes: it is a reminder to patients to eat properly, and it is a springboard for conversation about patients’ eating habits that have led to poor scores. By these tokens, dialysis staff seek to enforce dietary compliance.

A second or informal mode in which staff exert power over patients involves mechanisms of social control. Much of the literature on forms of social control reveals that it occurs in face-to-face communities, particularly in the Mediterranean (Bailey 1971). We can draw upon that literature for some helpful insights into the meaning of social control practices because the dialysis setting or “community” is also small, open, and highly interactive. A person’s reputation can be seen as a source of their power. “A man’s reputation is not a quality that he possesses, but rather the opinions which other people have about him” (Bailey 1971:4). One form of social control is through damaging a person’s reputation via gossip and ridicule. The subject of gossip is the ranking and evaluating of others based on local social and moral criteria (Hutson 1971:45). Gossip serves a moral function: “an assessment of the behavior of others can be understood as a claim on the part of the speaker to a particular moral position and status” (Codd 1971:185).

Moreover, gossip is “designed to tell the hearer not only about the other person concerned (alter) but, more importantly, about the relationship between the speaker and that person (ego and alter)” (Codd 1971:185).

According to reports by patients on the Internet, the staff at other dialysis centers had announced to the entire unit which patients had gone over their dry weight<sup>49</sup> at each treatment. One patient on the Internet reported that the unit attempted to implement a public form of recognition of patient compliance behavior: the unit was going to start posting everyone’s labs on a wall chart. Those who did well were to receive a little stars by their name, while those who were noncompliant were to receive a frown by their name. The patients rebelled because it jeopardized patient confidentiality and the idea was called off. Another Internet patient said:

“I get upset at our unit when the nurses talk about the people who are up on their dry weight too much. They talk about them in front of everyone, as if they were mannequins. Seems to me they could give those noncompliant folks some counseling or try to give them some sort of game plan to help them. Instead they just criticize them. And I have seen them ignore them or say it is their own fault when they start cramping or vomiting” (5-28-98).

We can interpret these staff behaviors by drawing upon the social control theory presented above. First, the staff apparently desired to gossip about noncompliant patients among the entire group of patients in order to reinforce the medical standard of compliance with the medical regimen. The medical standard is also inherently a moral standard. Patients ought to take personal responsibility for their health.<sup>50</sup> Those who have not taken responsibility are publicly humiliated into conforming with the medical regimen. Second, the staff’s behavior also

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<sup>49</sup> Each patient has their own “dry weight” -- the weight at which blood pressure is normal and no swelling is present. Patients who gain much weight from fluids between dialysis treatments often experience muscle cramping as a result of pulling off fluid. The more fluids ingested, the more cramping is likely to occur because of the need to remove enough fluids to return to the patient’s dry weight.

<sup>50</sup> Issues of noncompliance and personal responsibility for one’s own health are explored in further detail in Chapters 9 and 10.

served to reinforce the power structure within the dialysis unit. Through ridiculing noncompliant patients, the staff simultaneously exercises and demonstrates their authority over patients.

There are several informal ways in which staff inadvertently diminish patients' power. Each way pertains to patients' perceptions that the staff provides impersonal care. First, some patients (n=5) reported that they felt that the staff's care was not sincere because patients were not given a chance to communicate with the staff about their problems. For example, Chantal articulately expressed her "wishes that there was more time to express how you feel, but there is no time because the techs and staff are too busy setting up and getting ready for the next patient that there's no time to express how you feel to the techs/staff." This patient had observed that "other patients are depressed and angry" and should be given an opportunity to "vent" and "express what they felt."

One such patient, Sandy, explained that she did not like the staff because, for instance, "they look at you without speaking to you." She had told them about her medical concerns (e.g., look at the access, there's a problem) but she reported that they said "it's no big deal," as if her concerns were not important. Consequently, this patient does not want to tell the staff about her problems because she thinks they will not do anything about them.

The work by Elliott Mishler (1984) can help us understand why this communication problem occurs. Mishler (1984) delineates two voices in the medical interview: the "voice of medicine" (biomedical, clinical information) and the "voice of the lifeworld" (social, contextual information). While physicians and other clinicians focus on the former, patients focus on the latter. Thus, a main source of frustration for patients is the difficulty communicating physical symptoms which are related to life stresses.

A few patients (n=4) also expressed discontent with their care because they felt like they were in a factory on an assembly line. For instance, one woman, Sandy, felt like she was being treated like another “statistic,” and that she was on an “assembly line” since the next person seemed more important to the staff. Douglas believed that the dialysis management gave patients a “hard time” in that it “doesn’t care about patients” and “treats patients just like numbers.” Joseph also noted how “the people are friendly, except that when it’s time to come off, [he is] treated like it is a factory.” The perception that staff provide impersonal care which fails to address patients as whole individuals has been noted elsewhere (Kutner 1987; Alexander 1976, 1980, ).<sup>51</sup> Experiencing impersonal care is a problem because it inadvertently diminishes patients’ power by dehumanizing them.<sup>52</sup>

Third, the staff and/or dialysis facility undermine patients’ power by communicating poorly to patients in general and about upcoming changes in their treatment. Some patients (n=6) reported that dialysis staff seemed to disrespect patients when they communicated. Many patients on the Internet reported that the staff is condescending to patients. One patient in this study, Carl, asserted that he did not like “the way they [the staff] talk to you in general, like talking down to you.” An example of the disrespect toward patients is the staff’s reaction to patients who are experiencing muscle cramping. According to many patients, staff members tell patients that they are “at fault” and responsible for the cramping due to their weight gain between dialysis treatments.<sup>53</sup>

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<sup>51</sup> See Chapter 1 for a lengthier review of Linda Alexander’s (1876, 1980) analysis of this issue.

<sup>52</sup> Elaine Scarry (1985) found that the same process occurs but, intentionally, to justify the practice of torture.

<sup>53</sup> Few patients (in the study and on the Internet) reported that they have also had staff who responded nicely to their cramping. For instance, some staff members asked the patient what he wanted to be done when he started to cramp. When Jerome asked to stop the machine from drawing liquid, but not from cleansing the blood, they did this for him.



Dialysis centers also make changes to the structure of medical practice without informing patients. At one point, a dialysis center switched patients to different units in order to organize the same types of dialysis machines into one unit. Two patients (Pauline, Michael) voiced their dislike of this practice because they were not informed of the reason for it before it occurred. Consequently, Michael noted that the management was “herding people around like cattle by changing their units.” Switching units was a problem to him because he had:

“built up friendship[s] with people [but they] switch people when they build up friendships... They never ask you, do you want to switch units. They don’t ask you to switch, they don’t let you know about it. They don’t ask you how you feel about it or not.”

Thus the nature of and lack of communication between patients and staff minimize patients’ control over their health and their treatment. In addition, this practice reflects a lack of consideration of patients’ social organization.

So far we have seen myriad examples of dialysis staff exerting their control over patients. Patients responded to this behavior in two ways. One way was by accepting the behavior and keeping a low profile. The other way was to speak up to resolve patient-staff problems. This latter response will be described in light of patients’ reactions to dialysis facility policies.

A few patients revealed that they were afraid to speak up and report problems about staff. An outspoken patient, Juliet, commented about why this happens: “a lot of patients don’t open their mouths because they’re afraid of being retaliated against.” In a sense, the staff have some degree of physical ‘power’ over patients, in that they could alter the way they insert needles or adjust the blood pressure thereby causing pain; whether or not they purposely do so is unknown.

According to an anecdotal report by Michael, when patients requested to be taken off the machine, some technicians refused to do it. Another patient, Jerome, similarly recognized a fine line between complaining and staff reactions. He said, “I don’t want to complain [and] don’t

want to ask too much [because] they're busy." Having sat next to a patient who was a 'complainer' Jerome observed that the staff will "have respect for someone who doesn't hassle them [since] they know it's legitimate when you ask for help." It appears that some staff make a distinction between problems that result from the patient's own "fault" and those which are "legitimate" or uncontrollable and react differently to each problem.

### Dialysis policies and rules

Dialysis facilities have a number of policies and rules by which patients are expected to abide. Violation of these rules is usually documented in the patient's chart, and, if done repeatedly, may ultimately result in the patient being transferred to another dialysis facility.

Dialysis facilities in this study have stipulated policies against patients eating and drinking while on dialysis.<sup>54</sup> This rule was established by the Ohio State Health Association (OSHA) as a health safety precaution. The basis for this rule is that food can touch dialysis equipment and blood products and thus facilitate the spread of blood borne infections such as Hepatitis B. Since OSHA conducts surprise visits it could unexpectedly shut down dialysis facilities if representatives witnessed patients eating. Facilities differ in how stringently they require patients to follow this rule. The legitimate exceptions to the rule include consuming cups of ice provided by the facility (to satisfy thirst without causing fluid overload), crackers or cookies (in case of a sudden drop in blood pressure), and hard candies (which are individually wrapped and unlikely to come into contact with blood products). Some patients brought in sodas or small food items such as muffins, cookies without censure. Patients who brought in larger

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<sup>54</sup> There is a wide range of policies on eating in dialysis units. According to patients on the Internet, some centers allow patients to eat their entire lunch. At one such center (CMC) the staff even offered to purchase food for patients from McDonald's. There are also centers which forbid even hard candy and chewing gum. At one such center, a patient had experienced a drop in blood pressure and choked when eating and consequently, the patient's family is suing the dialysis company. Apparently, in France and Japan, patients are allowed to eat full course meals while on dialysis.

foods like hamburgers were warned, and staff even took away such foods from patients. Dialysis staff were thus under pressure from OSHA, like the psychiatrists were under pressure from state agencies, to ensure they follow policies appropriately, which meant that the staff had to restrict consumption in the units.

There were two patients whose actions defied two facilities' policies about eating and drinking. These two patients, Juliet and Malcolm, received much attention for their behavior and even threats from the staff to change their behavior. The dialysis staff thought in terms of these two patients when relating to the violation of policies against eating and drinking. The two patients were central to challenging and changing the policies and in so doing, shed light on the cultural themes of strained patient-staff relations.

At one facility, the staff believed that eating was getting out of hand among many patients, though particularly so with Juliet, a trim, 39 year-old woman. Although Juliet claimed that her nephrologist allowed her to eat on dialysis for medical reasons, the dialysis staff did not want her to eat because of the possibility of getting blood borne infections. The facility sought to crackdown on patients' eating activities to stop them altogether. At that facility, signs were posted all over that read "Attention. In compliance with O.S.H.A. and the state Department of Health Regulations for infection control, there is to be no eating or drinking in the hemodialysis unit. Thank you for your cooperation." Minutes before interviewing Juliet, I observed at least three staff members talking about Juliet and her eating problems. One nurse in particular honed in on Juliet's eating by quickly approaching Juliet's chair from the center of the unit intermittently to check on her. Juliet had just sat in her chair and her spouse came by with a plastic bag full of things. Quickly, Juliet pulled something out of the bag and hid it in her blankets. Juliet was weary of the nurse's tactics saying that her "radar is growing." The nurse

immediately swooped down to her, like a vulture, all the while in a semi-crouched posture with her hands outstretched in front of her and reached for the bag and opened it up to look inside of it to make sure there was no food.<sup>55</sup> Juliet interpreted the crackdown against food as an issue of “fairness.” She noted that other patients brought in food too “but I was more obvious and the others would smell it and would want to eat too.” Juliet was happy to share but recounted that when she once did, was harassed by the staff because of the harm french fries can incur (due to their high potassium and salt content). She believed that the signs against eating were her fault. What upset Juliet was that there seemed to be a double standard about eating in the facility since patients brought food for the staff who ate it in an adjacent staff-only room. At the end of the interview, Juliet nudged me with her foot to indicate that the patient next to her was openly eating a muffin without any attention from the staff! Because of her eating and other rule-violating behavior (see below), Juliet was eventually transferred to another facility.

The second patient, Malcolm, also had a reputation among staff for being ‘manipulative’ because his actions that countered his dialysis facility’s rules. Malcolm recounted a few stories of how he challenged facility rules because he did not allow people to control his body. For instance, one staff member established a rule that limited patients to two small Styrofoam cups of ice. Believing that this rule was arbitrary, Malcolm brought in two large cups and filled them up. The staff then abolished the rule. Malcolm also related how he once had his young children visit him at the unit. The same staff member must not have thought that that was such a good idea, so she established a rule against allowing children in the unit. But Malcolm observed that other

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<sup>55</sup> When this happened, I was standing watching all this about 5 feet away waiting for Juliet to get hooked up. Later on, Juliet tried to pry open a can (of potato sticks) she had hid but it would not give. So she asked if I could reach over to the nearby table and get the scissors. I did though felt like I was an accomplice to a crime! While she ate the potato sticks, a different tech came by to check up on her, and Juliet said “I can tell [the tech] anything” even eat in front of her. This event points up the staff’s inconsistent approaches to carrying out policy.

patients' adult children were allowed to visit. He then challenged the rule on the grounds that children are children regardless of age.

These two patients' actions represent efforts to empower themselves against rules that seemed arbitrary to them. The contestation of rules was implicitly a contestation of the staff's authority since they were the ones to communicate and enforce those rules. Thus, by contesting the rules, these patients (and others) generated interpersonal tensions with dialysis staff. Hemodialysis patients have also been reported to protest against the management of dialysis facilities in France (Waissman 1985). Waissman recounted how a group of dialysis patients went on a 'therapy strike' to protest against the center director's poor maintenance of dialysis machines. As part of their protest, patients blocked the director inside his office until he signed an order for new machines, which he did. As Weissman posits, the patients' actions made sense within the wider cultural context because the center was located within a working class neighborhood which was governed by leftist, primarily Communist parties. Patients organized like a labor union and went on strike (by not showing for treatment) in an attempt to bargain with the director who was perceived to be the "'boss' of a 'business' that was 'exploiting' patients and 'soaking the money out of them'" (1985:132).

Another policy issue pertains to patients' time of arrival for dialysis treatment. Being on-time for dialysis is important. The patient schedule is organized to maximize the number of patients doing dialysis during the span of a working day (and thus financial reimbursement from Medicare). This situation is similar to how hospitals are organized to move or "turf" (Shem 1978) patients in and out of wards as quickly as possible, rather than making the environment or building comfortable for patients to relax in (Rhodes 1990, 1991). At some facilities, when patients arrive late, they can throw the whole schedule off in a given unit. That is because when

the next patient arrives to dialyze, he or she must wait as the previous patient continues to dialyze, making up for lost time.

It is essential that patients get enough time to dialyze to filter the toxins from their blood, among other things. Some dialysis facilities have taken measures to prevent late arrivals from interfering with the patient schedule. Should patients arrive late, their time on dialysis is shortened so that they finish as originally scheduled. This measure prevents patients from obtaining their required time on dialysis. Yet the dialysis center management believe that patients are responsible for their own schedules. But there are always patients with valid reasons for arriving late, e.g., fatigue, problems with transportation, and who desire to receive the full duration of their dialysis treatment. However, these dialysis facilities require that patients sign a form signifying patients' acceptance of responsibility for arriving late and cutting their time since reducing dialysis time can cause medical complications. This form is also kept in the patient's medical record to absolve the dialysis center from responsibility in case related medical complications occur in the future. Like the dietitians' "report card," the form for leaving early is another part of the medical record which keeps track of patients' noncompliant behavior.

One patient, Monique, expressed her dislike of this policy by stating: "I don't like it, I didn't ask to cut my time" and suggested that there be more space between patients in case some are late so that they would not have to have their time cut against their wishes. Dialysis patients on the Internet have voiced their concern that such practices are unethical because of the harm incurred for shorter dialysis runs, especially when they could not help being late.

Juliet had also arrived late one day because she was sick. She recounted how a nurse's reaction to her tardiness seemed to be a form of exerting control over her. Juliet related that even

though she had called the unit to inform them she was going to be late, her nurse got “mean on her” and told her, “it’s an inconvenience for everyone.” In response, Juliet thought aloud,

“do you want me to get on my knees and ask for forgiveness? It’s like having a parent instead of a professional-patient relationship! ... Most of them [staff] have control problems. They think that since you’re here three hours a day then they have control over you... because they tell you what to do and see you at their own convenience.”

This discussion has shown that power is diffuse, both staff and patients seek to exert their control within the context of dialysis. Patients’ responses to dialysis policies show that they have ways of empowering themselves in a context where patient-staff relations may be strained. Patient protest instead of patient compliance has been found to be common in other American institutions (psychiatric hospitals) (Hershel 1992) since “the authority of institutions is in direct contrast to the idealized values of the culture: the impersonal authority of the institution over the individual conflicts with a sense of individual rights” (Hershel 1992:314).

This discussion of patient-staff interactions is important because it reveals aspects of everyday life on dialysis for patients as well as introducing the moral significance of noncompliance among dialysis staff. The issue of noncompliance, as we will see again in Chapters 9 and 10, is key for understanding how dialysis professionals’ perceptions of morality affect their provision of care to patients.

### **How Dialysis and ESRD Changed Patients’ Life**

Most patients found that ESRD and dialysis have greatly affected their lives. The impact of ESRD on patients’ lives can be described in terms of four core issues: 1) bodily concerns, 2) worse health, 3) changes in self-identity, and 4) lifestyle changes. Some of the more representative comments patients made about dialysis are presented below. Poems by patients on the Internet are also presented to facilitate understanding of patients’ experiences.

### Bodily changes

The most common sentiments about ESRD and dialysis pertained to bodily concerns. The most immediate concern is the pain. Everyone hated being “stuck with the needles all the time.” In addition, while on dialysis many patients experience discomfort from nausea, dizziness, fatigue, and cramping. Patients also reported that they disliked how their body and appearance changed. Dialysis can change patients’ appearances in different ways. For instance, it darkens their entire skin, and even creates tiny bumps on the skin. The graft in the arm creates snake-shaped bulges that can grow as big in diameter as a banana four inches long. In addition, bruising often results from the daily needle sticks. Some patients felt embarrassed showing their graft sites in public since strangers sometimes stared and accused them of being drug abusers. In addition, patients disliked the fact that dialysis dried their skin which caused severe itching.

### Worse health

A second common experience is that ESRD generally leads to worse physical and mental health, as four patients noted. Patients were tired and found it difficult to exert the energy required to engage in physical fitness and even daily chores, like housecleaning and cooking. Patients described these experiences in the following:

Clarence: “I am no longer physically fit, no longer feel healthy. I have to be more disciplined. I have to slow down a lot more... I used to spend a lot of time running in the streets.”

Pearl’s life has changed: “a whole lot [since] I used to be more active in a lot of things [and now] I try to do [things] but can’t... I used to get up and clean my house [but now] I have to pay people to clean.”

Two poems and one haiku shed light on the extensive effects of dialysis on patients’ health and lifestyle, the latter one does so with a humorous tone:



A Psalm of Dialysis

So strict is my diet, I must not want;  
It maketh me to lie down at night craving;  
It leadeth me past bars and restaurants;  
It tryeth my willpower.  
It leadeth me in paths of saltless foods  
For my heart's sake.  
Yea, though I walk through the aisles of the produce department,  
I shall buy no bananas,  
For they are loaded with potassium;  
The avocados and the grapefruit they tempt me.  
Before me is a table with no milk,  
But bottles of Phos-los and Tums;  
My day's quota runneth over.  
Surely critical nurses and dietitians shall follow me  
All the days of my life;  
And I shall dwell in the fear of the scale  
and the sphygmomanometer forever.  
*--Anonymous*

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Ode to a Grecian Urinal

Oh where have gone the days of olden,  
When often flowed that liquid golden?  
And what to do with memories mellow  
Of winter fun and snow that's yellow?

But that was then and this is now  
The pump went bad; I'm not sure how.  
And so I think I've lost a friend,  
A loss that's hard to comprehend.

What used to come so naturally,  
Machines will do, instead of me.  
The sound of that relieving rain  
Is Muse to this forlorn refrain.

So warm, relaxing, cleansing streams,  
Now only visit in my dreams.  
I never knew how much I'd miss -  
The lovely, gurgling sound of piss.  
*--Paul Baines*

Dialysis Haiku  
Scales needles saline  
the chairs and television  
strange tools for caring  
--Raymond Dinkin (1998)

One-fourth of all dialysis patients are depressed (Stewart 1983). Depression is a common response to the myriad losses that occur at the onset of illness, including job loss, financial loss, loss of friends and group membership, restricted lifestyle and mobility (Stewart 1983; Petrie 1989). In addition, the development of strained relations with support groups (friends, family) also leads to emotional distress among dialysis patients. Dialysis patients and their spouses experience high levels of psychological distress and problems with sexual enjoyment (e.g., impotence in men) (Soskolne and Kaplan De-Nour 1989; Holcomb and MacDonald 1973). The death of other dialysis patients can be a devastating experience for fellow patients (Stewart 1983), especially since peers constitute a source of support (Kutner 1987).

Many patients reported that their poor health and inability to do things consequently made them depressed. For instance, Hazel expressed that she was “depressed a lot [because] I can’t go like I used to [and] I have to depend on someone else. [This is upsetting] especially when you’re used to doing for yourself.” This sentiment not only reflects the American values of independence and self-sufficiency, but also shows how the failure to achieve these values can generate mental health problems. This cultural pattern of patients’ responses to the inability to physically practice what they value can thus be seen as an ethnopsychological construction (see Gaines 1992d). The desire to regain energy to engage in activities patients enjoy and to live in an independent manner play significant roles in their decisions to seek a transplant.

Dialysis patients who cannot adapt to dialysis often resort to suicide. One patient, Luke, who had once attempted suicide (over the course of the study) said frankly, “I ain’t the happiest

person in the world right now. Obviously, if you try to blow out your brains it [dialysis] has some effect.” Renal dialysis patients have a higher incidence of suicidal behavior -- up to 400 times higher -- than that found in the general population (Abram, et al., 1971). The relationship between experiences of physical and mental health and treatment choices will be shown in Chapter 7.

### Self-identity

Third, dialysis altered patients' sense of self identity (Hallowell 1955; Kutner 1987; Gerhardt 1990; Charmaz 1995). Two patients, for example, missed weighing more than then do now. Bruce, who went from weighing 210 lbs. to 180 lbs., explained that his former greater weight made him “feel a better person” and “more confident.” For other patients, dialysis created a divide in the relation between body and self.<sup>56</sup> For instance, Emmanuel noted that “on dialysis, your body belongs to your self no more...your doctors own your body.” We can interpret this patient's statement in two ways: first, he may have referred to physicians making money off of patients' sick bodies, and second, he may have referred to the fact that physicians meticulously keep track of all aspects of patients' blood chemistry. Similarly, another patient, Sandy, commented on her transformation of self identity with reference to the incorporation of the dialysis machine into her identity: “the machine follows me wherever I go and I can't go anywhere without the machine.” This transformation represents what Donna Haraway (1991) would call 'cyborg' identity in that human and machine merge to the extent that part of the individual's selfhood encompasses the introduction of the machine element.

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<sup>56</sup> Experiences of self/body separation have been examined in the context of torture and pain in the work by Elaine Scarry (1985). Scarry contends that through torture and pain, a person's sense of self is destroyed because there is no language to describe such an existence.

Several patients' (n=5) self identity changed because they had to stop working altogether or work less. For 31 year-old Mindy, "By being on dialysis and losing so much I feel inadequate ... [at my age] I should be working, but depend on a machine." Four Caucasian men also recounted significant shifts in their self identity and what Charmaz (1987, 1995) calls "identity goals." Identity goals are "*preferred identities* that people assume, desire, hope, or plan for" (Charmaz 1987, emphasis in original). People with chronic illnesses, Charmaz explains, often initially plan to resume their lives after the onset of the disease, however many people must make identity "trade-offs" and lower their goals to match their lessened capacities (1995:660). All of these men had been highly successful in their full-time jobs but had to reduce their work load because of the need to adapt to changes, particularly, fatigue and time constraints that ESRD and dialysis impose on the body. The change in work schedule consequently affected these patients' personal identities. For instance, one of these men, Henry, a self-described "type-A personality" and work-a-holic involved in community health care and social justice became disappointed that he could no longer maintain his old schedule. Henry explained how dialysis affected his work and personality in the following ways: "I used to lead the pack and I'm lucky to be able to follow" and "I am not as dependable as I want to be. I used to be very prompt." Another man, Irving, who had to turn down a much sought after corporate position, succinctly stated, "Dialysis does not facilitate career goals because of the exhaustion." Dialysis patients' sense of self-identity based on the world of work has been shown elsewhere (Waissman 1985; Gerhardt 1990). For instance, Gerhardt (1990) found that male dialysis patients shifted their gender identity from the traditional male role as the bread winner in the family to having to depend on their wives' employment to sustain their livelihoods. As shown in Chapter 7, employment status factors into some patients' decisions about treatment for ESRD.

## Lifestyles

Fourth, patients' lifestyles were dramatically altered due to concomitant financial and physical limitations. Among the sample of patients, 43.0% as individuals and 60.8% as couples lived in households below the federal poverty line according to their income level.<sup>57</sup> These data are similar to those found by Evans, et al., (1985) who found that two-thirds of patients (n=859) were receiving federal income support, yet 30% of them lived below the poverty line. Patients have difficulty receiving less money and receiving money less often than what they had been accustomed to before ESRD. Forty-nine year-old Virginia explained, "I have been working since I was 17 and all of a sudden not working and getting one check a month is really depressing." People's lives and lifestyles changed dramatically since they no longer have the money they used to have. A decrease in finances meant that some patients had to use public transportation instead of driving their own car, use a relative's phone instead of maintaining their own phone, eat more bland foods instead of cooking with expensive spices<sup>58</sup>, etc. For some, the decrease in finances signaled a shift from being independent to relying on others for daily support. For instance, patients had to rely on family members to drive them to the dialysis center, or to purchase groceries for them, among other things. As we will see in Chapter 7, financial limitations can effect patients' treatment decisions.

Only those patients who maintained a full-time job after starting dialysis felt that ESRD had little impact on their daily lives. Perhaps a full daily routine demands that patients regulate

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<sup>57</sup> The Federal government poverty guideline in 1997 considered an individual indigent if the individual's monthly income was \$670 or less. In contrast, states have different standards to qualify for indigent aid. To qualify for Medicaid in this state in 1997, an individual's monthly income was \$418 or less. In addition, to be eligible for Medicaid in this state, an individual's assets must amount to \$1,500 or less. The qualifications also vary for married couples.

<sup>58</sup> Because the renal diet requires patients to limit their salt and fat intake, many recommended foods tend to be bland in flavor. However, dietitians suggest using different types of spices in cooking meals.

their health more meticulously. Two full-time employed men, commented on their lives since starting dialysis:

Lewis: "My life hasn't changed that much because I still work everyday, I still go out... I know if I don't do it [dialysis], I'm going to die. It's not bad. I can't say I enjoy it. It's like a part-time job. I go to work in the morning and come here at night. It's something I know I got to do."

Albert: "I have to take care of my self much better. There are limits to everything you do. Fluids, foods, certain things you can or can't eat. I can do basically what I did before... I'm 1/8 of a slower pace at work."

Another change in lifestyle pertains to shifts in daily schedules due to the time limits dialysis imposes on daily life. Because dialysis takes up a large portion of their time weekly, many patients felt that dialysis consumed their lives to the point of controlling it. People must plan their days around it, and maintain a very regimented schedule. Two statements that represent different perspectives about time and dialysis are the following:

Roland: "It takes up, it controls a big part of my life. I have to give attention to it even if I don't like it. It breaks up my day. Life goes on."

Chantal: "[My] whole life is surrounded by this. It's limited, there's so much to do... You have to work it into your schedule."

### **How Patients Adjusted to Dialysis**

Adjusting to dialysis is a long and difficult process. Patients' reactions to having kidney failure are similar to the grieving stages identified by psychiatrist, Elisabeth Kübler-Ross: denial, anger, bargaining, and depression (Kutner 1987). According to one clinical psychologist, patients go through several stages of adjustment to renal disease, known as the GRACE model (Haney 1993).

The first stage is grief in reaction to the losses of freedom due to treatment times, loss of health and well-being, loss of income and career, and possible loss of intimacy and relationships. The second stage is rage: patients commonly experience an emotional backlash, anger at the 'unfairness' of having the disease and at the limitations of treatment. Acceptance is the third

stage, in which patients come to calmly evaluate their status and gather personal resources. The fourth stage, compensation, is the process of adapting to the new situation by compensating for losses. During this longest and most difficult stage patients find new ways to accomplish necessary tasks, establish a new routine, and forge new relationships. The final stage is equilibrium, when a satisfactory balance of capabilities and limitations has been reestablished. Patients often retreat into previous stages as they experience episodes of morbidity. The extent to which patients adjust to dialysis will be shown in Chapter 7 to play a significant role in treatment decisions.

Patients in this study learned to cope with it through various distinct ways. Some patients relied, for example, on their personal strength after accepting the reality of their situation. Patients' statements reflecting this mental effort are as follows:

Chantal: "There was no choice [about adjusting]. The first step is disbelief, the second is anger, the third is denial. Then you get to the point of this is how it is. You adjust your mind [by thinking] this is how it is, [this is] what is necessary for survival."

Mark adjusted to dialysis by: "knowing I needed it, by coming."

Another patient, Douglas, recounted how he had been depressed for the first 1½ years and so he missed a lot of dialysis treatments, which ultimately landed him in the emergency room. At that point he admitted to himself that "it's the way it's going to be." He started to accept dialysis because "I got sick and tired of being sick and tired." Douglas explained how, after 2-3 years, he came to accept dialysis:

"I had to do what I had to do. I had no choice. The more I resisted the more it hurt me. The best thing to do is to accept it. I changed my attitude and make the best of it. I got to be here in order to be kicking. It's easy to give up, harder to accept."

Patients also reported that they adjusted to dialysis either by comparing themselves to others with ESRD or to patients who seemed to have more serious medical conditions. In other

words, patients put their situation into perspective by realizing that they could be in a worse medical situation than they currently were in, or by observing other ESRD patients who were faring worse than they. Patients made the following remarks about this process:

Pauline: “[What helped me adjust was] the thought that it could have been worse; it could have been cancer.”

Monique: “It’s not as bad as I thought it would be ... I thought it would be terrible, I’d be super sick all the time... I didn’t know what to expect.” She explained how she came to adjust to dialysis: The first day she “saw a little boy doing what he had to do, taking it like a man, and I’m sitting here, crying like a baby.” He was her “inspiration.”

Marshall: “I look at other people and count my blessings - just by looking at other people. It [dialysis] ain’t the worst thing in the world.”

According to medical sociologist Nancy Kutner (1987), patients adjust to dialysis by developing support networks with other dialysis patients and staff. Like the patients’ comments presented above, Kutner found that patients get reassurance by seeing other patients cope with ESRD. Specifically, “comparing one’s own experience with that of others serves a ‘normalizing’ function as well as an educational function; by talking with others, said one man ‘you can find out what is normal and what is not normal to a certain degree’” (1987:57). In both Kutner’s and these study data, adjustment to ESRD is largely based on comparison to other patients.

Dialysis social workers (Debbie and Erika) and nephrologists reported to have observed “ethnic” differences in how patients adapt to dialysis based on their experiences working at various dialysis centers with different types and proportions of ethnic groups, e.g., European American and African American patients. Without specifying which groups, the social workers noted that some groups of European American patients tend to have a more difficult time adjusting to dialysis than African Americans. Empirical studies show that “blacks” do better on dialysis than “whites” by having lower mortality rates (Dan Gordon 1990). According to the social workers, European Americans are overwhelmed and distressed by their need for dialysis, and wonder “well, I did everything right,” “What have I done wrong?” and “How can it happen



to me?" The lack of a broad source of family support also makes adapting difficult; many European Americans have family members scattered about the city or country. European Americans tend to resist relying on family for help because they do not want to impose on or burden them.

In contrast, many African Americans patients have lived in a cultural context in which they are more aware of the hardships of life so that they are better able to handle the burdens concomitant with dialysis. In addition, many African Americans are able to rely on their extended family members for help in getting through tough times (Stack 1972). Further, many African American dialysis patients rely on spirituality as a major form of coping (Stolley and Koenig 1997). According to Joanne, a social worker, those who have a strong need for control in their lives have a more difficult time adjusting to dialysis than those who have an inner peace with dialysis by leaving their concerns for G-d to manage. The capacity to adjust to dialysis affects patients' desire to seek an alternative treatment. Since there is evidence that ethnic groups cope differently to dialysis, it is likely that there are ethnic differences in treatment decisions. This issue will be explored further in Chapter 7.

In this section we have learned much about patients' experiences with ESRD. This depiction is based on primarily patients' accounts. Another view of patients' experiences is provided to us by nephrologists based on their clinical interactions with patients. Their perspectives are presented below.

### **Physicians' Perceptions of Patients' Experiences with ESRD**

Three nephrologists commented on the recent historical changes in patients' perspectives and expectations about renal replacement therapy and how these influence patient-nephrologist interactions. Dr. Julian, a transplant nephrologist, explained how in the 1980s, dialysis was

perceived as ‘miraculous’ and so the attitude of patients and HCPs was different back then. At that time, people were amazed at being alive when they thought they would be dead. They were grateful for being alive. Nowadays he finds that patients expect more quality of life issues to be fulfilled and so dialysis has become routinized. A French nephrologist further describes this trend:

“Fifteen years ago ... some patients were big problems... . When they were connected to the machine, it was a resurrection for them. Nowadays, there are no more problems with dialysis .... Consequently, patients are not happy because the coffee isn't hot” (Waissman 1985:132).

In the early days of dialysis, patients started dialysis late in their ESRD, after they had become uremic<sup>59</sup> (Reichsman and Levy 1972). Today, nephrologists try to start patients on dialysis early, before they become uremic to facilitate a smooth transition to treatment (Stewart 1983). The change in timing of dialysis initiation corresponded with nephrologists’ perceptions of changes in patients’ attitudes about dialysis and their life in general. In 1983, one nephrologist made the observation that:

“Before 1973, when patients were carefully screened for dialysis, those who were accepted were grateful for the chance of life. They often experienced euphoria and a sense of well-being during the first couple of months. I have not found this to be a common phenomenon today. In observing new patients placed on dialysis in a county hospital over the past four years, I have found that patients view dialysis as evidence of failure rather than a lease on life. They experience fear, anxiety, and depression rather than euphoria” (Stewart 1983:624).

Two dialysis nephrologists in this study also witnessed changes in the way patients have come to regard their care and caregivers by reference to a Chinese proverb, called the Yangtze River story. The Yangtze River story is about how a person, (who we’ll call Joe) goes to the river to commit suicide but someone stops Joe and so Joe lives. But Joe feels that the savior is indebted to him by dint of being kept alive. Joe then expects the savior to make life worth living for him, since otherwise he would have died.

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<sup>59</sup> Uremia is the condition in which the kidney function fails and there are excess toxins or impurities in the blood.

Dr. Olson said that the Yangtze River syndrome applies to dialysis patients more than any other kind of patient because they are kept alive by machines. They would have died had it not been for the doctors and machines. Many dialysis patients therefore expect others such as family members, social workers, nurses, and nephrologists to take care of them in all aspects of their lives. He gave the example of how the clinic helps to organize patients' lives by setting up their appointments in advance instead of patients calling the front desk to arrange their appointments themselves.

Another nephrologist, Dr. Nicola, explained how dialysis patients exhibit the same attitudes of 'Joe' depicted in the Yangtze River story, particularly in a case of noncompliance. When patients are not taking their medicines, Dr. Nicola will sometimes recruit their family members to help the patient take their medicines. Dr. Nicola (paraphrase) related the story of how he got one older woman to do dialysis who was reluctant to do so even though she had a high potassium level and was going to die if she did not have dialysis. He recalled: "I spoke to her son who got the rest of the family to gang up on her to come in for dialysis. She's been coming in now for two years and she avoids me and hates me. It reminds me of the Chinese Yangtze River story of a person saving someone from suicide. Now I feel indebted to that person for keeping her alive. Sick people seem to shun talking about their health, and keep it secret. When the family hears about the sick person's condition, they say 'I can't believe it happened' and start to help." These nephrologists' accounts reveal that advances in medical treatment correspond to changes in patients' experiences of treatment. Over time, some patients have taken for granted the gift of life wrought by dialysis and have instead focused their energies on improving their quality of life.

This chapter has provided an account of the types of healthcare professionals involved in dialysis and transplantation, the nature of their work, and the settings in which they care for patients. In addition, this chapter has portrayed the experiences of dialysis patients participating in this study. This background information is important for understanding the context of healthcare professionals' and patients' treatment decisions. Patients' treatment decisions, as we will see in Chapter 7, are largely informed by their attitudes and experiences of dialysis, rather than larger life goals. The following chapter delineates in greater detail dialysis professionals' decisions about communicating with patients about their treatment options.

## **CHAPTER 6: NEPHROLOGISTS' COMMUNICATION WITH PATIENTS ABOUT TREATMENT OPTIONS FOR END-STAGE RENAL DISEASE**

In the previous chapter we learned about the roles of all clinicians who take care of dialysis patients. We also reviewed the nature and extent of interactions between clinicians and patients. What we have not yet learned is the content of their discussions, namely, that which nephrologists communicate with patients. Although nephrologists discuss many different issues with patients, we are primarily concerned with how they talk about treatment options for ESRD. This communication process between patients and clinicians is important because it effects how each party makes treatment decisions.

The question guiding this analysis is: Do nephrologists' decisions about the communication of treatment options affect patients' access to kidney transplantation? Nephrologists' decisions would affect patients' access to transplantation by influencing their treatment decisions. We can answer this question by examining how nephrologists discuss treatment options in terms of decision-making theory, as presented in Chapter 1. Nephrologists' decisions about when, what order, and to what extent to discuss treatment options, are examined in this chapter as possible mechanisms of framing treatment options or steering patients to one therapy or another.

This chapter concentrates on nephrologists' decisions about informing patients of their treatment options in terms of four variables: a) the timing of discussions about treatment options, b) the order of options presented, c) the extent of details presented about treatment options, and d) level of encouragement to choose transplantation. Each of these variables is examined in turn, followed by a discussion about how the process of communication depends on both patient and physician factors. By deconstructing the sociocultural bases of their decisions,

we will learn why nephrologists communicate treatment options to patients over a period of time and how their communication process appears to be constrained by various conflicts of interest. This chapter also shows that while there is some degree of heterogeneity in nephrologists' communication practices, they act within a shared cultural value system about the meaning of information.

Interviews with nephrologists and observations of their clinical interactions with patients revealed that their information-giving of treatment options to patients occurs in a process. It is a process because nephrologists present information over time though not all clinic visits involved educational discussions. Nephrologists' information-giving is intricately related to when primary care physicians refer patients to them. Recall from Chapter 3 that primary care physicians varied in the timing of patient referral to nephrologists. Thus, the initiation of, the sequence of, and the amount of detail about treatment options that nephrologists present to patients depend, in part, on the timing of patient referrals in relation to how imminent their ESRD is. Patients who are referred early with progressive renal failure are likely to be presented with a greater variety of information about their treatment options than those who are referred late with a sudden onset of renal failure.

Below I present how nephrologists decide when, in which order, and how extensively to communicate to patients their treatment options, considering first those with a sudden onset of ESRD and then those with a progressive onset of ESRD. Excerpts from clinic visits with different nephrologists are included to demonstrate how their theory is put into practice.

## **Initiation of Discussion about Treatment options**

### **Sudden onset of ESRD**

The timing of nephrologists' first discussion of treatment options with sudden onset patients depends on clinical and nonclinical factors. In terms of clinical factors, nephrologists tend to wait until patients are medically and psychologically "stable" on dialysis to begin discussing alternatives to hemodialysis. This is because patients with a sudden onset of ESRD are acutely ill due to the build up of toxins in their body (uremia) which renders them generally unable to think clearly and makes them medically unstable. It takes some time to remove enough toxins from a patient's body for them to begin feeling able to learn more about their options. In addition, many patients experience psychological difficulty adjusting to dialysis; some patients reported that they cried for weeks when they first started dialysis. The time required for patients to become medically stable varies among patients, but usually, it takes from one to three months.

As Dr. Gilmore noted:

"Within 3 months. Some people just can't deal with it for a while. I don't know, just the psychologic trauma, being on dialysis is overwhelming, and they really can't start dealing with other things like transplant and alternative modalities for a couple [of] months."

Other nephrologists say that they will put medically unstable patients "on the back burner" before discussing transplantation and "pick up the pieces after the fact."

Nonclinical factors also influence when nephrologists educate patients with a sudden onset of ESRD. For instance, other life issues might need to be addressed first before transplantation comes up in the discussion. Dr. Easton explained why:

"It could be about a month, they can be stable, and then usually they come back for the first visit we can talk about different options... But you know, part of the thing is people who get started emergently are often people who haven't been to see a doctor, who don't have insurance, you know what I'm saying? It's also those kinds of issues, you know."

Dr. Easton implied that there are people with broader life problems, e.g., poverty, lack of access to health care, which must be addressed before discussing transplantation. She justified the delay in discussing transplantation with such patients by saying “unless they have a living related donor, it’s going to be years before they are going to get a transplant anyway.”

A second nonclinical factor explaining the delay in discussing transplantation with patients is structural in nature. There is a list of medically-based factors that nephrologists need to review with patients which are based on a form used in interdisciplinary meetings.<sup>60</sup> Since transplantation is listed last, Dr. Easton addressed it last.

A third nonclinical factor leading to the early timing of treatment discussions is the importance of instilling and maintaining the patient’s hope. For instance, Dr. Ingel briefly mentions transplantation to mentally stable patients when they initially begin dialysis in order to incur hope in this alternative to dialysis. Dr. Ingel related the story of why he presented all options to a twenty-three year old patient with sudden onset ESRD even the day before the first treatment:

“Because ... you’re going to tell him something depressing, you’re going to do something mean to him, stick catheters into him in various locations. The transplant is somewhat of a carrot, and it’s a psychological carrot that helps people get through that. And, there’s kind of a light at the end of the tunnel and so I think it’s important to present that in a very brief fashion and not go into a lot of details, by saying that, ‘We’re going to have to start dialysis tomorrow, but gee, otherwise you’re in good shape, and I think that, although many people do very well on dialysis, a kidney transplant might be something that you would do very well with and we’ll talk more about that down the line but that’s a way of avoiding regular dialysis treatment.’ And that’s basically what I would say at that time.”

As will become apparent throughout this and other chapters, the ‘discourse on hope’ similarly applies to nephrologists as it does to oncologists (DelVecchio Good, et al., 1990; DelVecchio Good 1991). Mary-Jo DelVecchio Good and colleagues found that oncologists’ desire to instill hope in their patients reflects various US cultural values. For instance, emphasizing to patients

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<sup>60</sup> The other items in the list (according to Dr. Easton’s memory) include: anemia, blood pressure, fluid, potassium, phosphorus, and renal osteodystrophy issues.



that the benefits of treatments improve with the advances of large-scale research studies on cancer suggests that cancer is curable. In addition, hope is infused with popular notions about the relationship between psyche and soma. Specifically, hope embodies US notions of personhood and autonomy in two senses: 1) there is an emphasis on individual 'will' such that if one has enough hope, one can make a change in the disease course in the body, and 2) people have the power to change their life course and body functioning. Unlike DelVecchio Good and colleagues' findings, we see that nephrologists seek to instill hope in patients to reduce patients' anxiety.<sup>61</sup> As we will see throughout this chapter, these themes about instilling hope pervade nephrologists' decisions about treatment information-giving. The similarity between oncologists' and nephrologists' practices may be due to the fact that cancer and kidney failure, as chronic diseases, have comparable mortality rates.

Nephrologists therefore vary in the timing of their education of sudden-onset patients depending on their assessments of patients' mental and psychological status. Although nephrologists may introduce the transplant alternative relatively soon after a patient with sudden-onset ESRD begins dialysis it is usually only briefly discussed at that time.

#### Progressive onset

Nephrologists use slightly different approaches for initiating discussion about treatment options for ESRD with progressive onset patients than for sudden onset patients. There are no established medical guidelines or standard procedures for educating patients in the early to mid-stages of renal disease progression (Falvo 1995; Hayslip and Suttle 1995). Currently, it is

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<sup>61</sup> The practice of oncologists withholding prognostic information to patients has also been shown to be done in Italy out of concern for overwhelming and causing anxiety in patients. However, this practice is mediated by cultural meanings of the relationship between information and anxiety (Deborah Gordon 1990, 1994).

up to the physician to decide what information is useful to prepare patients for ESRD and when it should be presented (Hayslip and Suttle 1995).

Nephrologists reported that they generally begin educating patients as early as possible in the progression of patients' kidney disease. The reasons for educating patients early are to help them get listed for a transplant sooner (to acquire waiting time)<sup>62</sup> and because their cognitive function becomes increasingly worse as kidneys become end-stage. However, as will be shown below, "early education" means neither comprehensive education on one occasion, nor education early in the onset of kidney disease, *per se*. Rather, it means conveying information about treatments over time when patients' renal disease begins to show signs of imminent or impending failure.

Most nephrologists determine when to start discussing patients' treatment options according to the rate of progression of the kidney disease. Some diseases progress at a slower pace than others, such as polycystic kidney disease (PKD). Nephrologists begin informing patients of their treatment options when they see that the patient's disease starts to rapidly progress. Thus, nephrologists educate patients "early" relative to the progression of the kidney disease rather than at the initial onset of kidney disease which can be stable over many years. The important distinction is between the onset of kidney disease and when kidney disease begins to progress toward failure.

Evidence of this style of patient management is apparent in nephrologists' use of measures of serum creatinine and creatinine clearance to assess the progression of kidney disease. For instance, several doctors said that when a patient's serum creatinine reaches 5 or 6

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<sup>62</sup> The longer patients wait on the national transplant waiting list, the more 'points' they receive; the greater number of points amassed, the greater likelihood of being called for a kidney transplant. See Chapter 3 for a discussion of the point system.

or when the CC is between 20 and 25 they inform patients of their options and refer them to pre-dialysis classes that teach patients about all options. A serum creatinine of 5 or 6 indicates that the end-stage phase of kidney disease is near. Dr. Testa made the connection between the pace of kidney decline and the measure of serum creatinine with regard to the education process:

"In a rapidly decaying kidney disease I would probably start at a creatinine of 3. In a slower declining kidney disease I would probably start [when] the creatinine [is] around 5 or 6. Again time frame I think to guesstimated end point would be probably the basis factor rather than an absolute physiological number."

In other words, this nephrologist and others begin educating patients earlier in their kidney disease when the disease is known to progress very rapidly. While nephrologists may inform their patients of the cause, pace, and specific progression of a patient's *kidney disease* early in its onset, they generally do not introduce information about treatment options until a patient's lab values (and symptomatology) indicate the near-future onset of *kidney failure*.

However, nephrologists also realize that they cannot wait too long before telling patients about their treatment options and preparing them for treatment. Informing patients too late tends to result in them starting dialysis in the hospital because patients are acutely ill, instead of in a dialysis unit prior to experiencing symptoms of uremia. As one patient noted, it is best to get the access surgery "out of the way before you get too bad so that recovery and training will not be stressful" (Dialysis Listserv 12-28-97). For Dr. Easton, allowing patients to get so sick they must go to the hospital to initiate dialysis instead of facilitating a smooth transition to dialysis is a sign of failure on her part. She conveyed the basis of her conviction in terms of helping patients feel better about doing dialysis:

"...I should know that they're going to take over and I should prepare for it so a patient doesn't go through the trauma. 'Cause that's part of why people feel so bad about dialysis is because you know, you're vomiting, you're this, you're that, you go to the ICU, they put a line in your neck, it's all emergent, and I don't think it's necessary. So I try very hard in my private practice, I mean it happens on occasion that you just really can't predict or somebody has a heart attack or something and that tips them over or something, but I try very hard to make an outpatient initiation. And then I think people have a much much better feeling about dialysis."

While there are diverse perspectives on when to educate patients, no one in this study reported to be in favor of late education. Dr. Lock explained why nephrologists have different approaches to the timing of patient education in terms of the nephrologist-patient relationship:

"I thought that there was a philosophic bias that different nephrologists held about the initiation of end-stage renal failure care. Basically the two poles of that bias are that you should start a patient early before they get a lot of complications of uremia, and so therefore you have to prepare them emotionally and so forth early on, which is kind of like hanging the crepe. Other people feel you should wait until they're *really sick*, really uremic, so that when they start dialysis, they will appreciate it. Because otherwise, what you were doing when you start a person before they feel sick from their uremia is that you are the bad actor, you are the one who caused all this hardship of needing to come in dialysis or to do peritoneal dialysis. I tended to err on the side of starting people early so that there wouldn't be emergencies and a lot of complications. I tried to justify that with a lot of rational teaching and talking to the patient... And, it carries a certain burden of convincing<sup>63</sup> the patient, if that that's the way to go. So that burden is on the physician to make the patient feel comfortable with starting early" (emphasis in original).

Without clear-cut guidelines, it is up to nephrologists to determine the appropriate timing to communicate treatment options with patients. Such communication tends to occur when a patient's kidney disease clearly progresses rather than at its initial onset. The fact that oncologists in the study by DelVecchio Good and colleagues (1990) were also found to provide patients prognostic information over time governed, in part, by the course of the disease indicates that larger biomedical and/or cultural values inform this practice. As discussed in Chapter 1, many healthcare professionals maintain similar approaches in their clinical practices because they ascribe to similar values within US biomedicine. That both nephrologists and oncologists engage in the practice of disclosing prognostic information progressively can be attributed to a shared understanding within medical practice. The basis of engaging in this practice can not be attributed to specialized training within medicine<sup>64</sup> since physicians of different specialties

<sup>63</sup> Convincing patients of their oncoming renal failure is difficult since many patients do not experience symptoms of uremia until it becomes too late. As Dr. Varga noted, "I think its very hard in medicine to try and convince people to do something when the beneficial effect won't be seen for 10 years or 20 years, you know, whether its an issue of lifestyle changes to prevent... kidney failure." This difficulty is exacerbated by the fact that patients may not feel any detrimental effects after delaying or missing their dialysis treatment since it may take months or years for the side-effects of uremia to develop to the point where patients feel sick. Six patients in this study reported that they delayed the initiation of dialysis because they did not believe they were really sick, as Roland noted, "I tried to run from it."

<sup>64</sup> Other studies have found that medical training facilitates its own approaches to clinical practice (Plough 1981;

engage in this common practice. Rather, it is likely that the culture of biomedicine, particularly among physicians who treat chronic illness, promotes a belief system that facilitates this practice.

Why do nephrologists wait until the disease appears to be steadily progressing to educate patients about their treatment options? The answer to this question requires the deconstruction of cultural beliefs informing their decisions. The shared biomedical value system governing the nephrologists' practice is manifested in several patient-related factors and two possible policy factors, which will be considered below.

#### *patient-related factors*

The patient-related reason often provided first is that nephrologists want to let the idea "sink in" that the patient has kidney disease. Otherwise, patients will get "overwhelmed" when they are told that they have kidney disease, need dialysis, and need to start now, as Dr. Olson stated.

A second reason is because patients may be very delayed in progressing to ESRD. Dr. Ingel explained this idea in the following way: "I don't find that it does any good to a patient to talk about dialysis if I see them for glomerulonephritis and they have a creatinine of 2.6 'cause it could be that they're just going to stay there for 20 years, whereas if it's 2.6 then 3.6 then 4.6, that's a different issue." Dr. Olson framed this notion in terms of "hope": "Depending on how serious the patient is, I let it wait because I don't want the patient to lose hope because the patient might not need dialysis after all, if the kidney hasn't fully failed." Thus, nephrologists' comments suggest that informing a patient prematurely can result in patients' loss of hope and unnecessary anxiety. It is interesting that in this context physicians consider premature

information unnecessary when in other medical contexts physicians consider it worthwhile, as in genetic screening for breast cancer (O'Malley, et al., 1997).

A third patient-related factor nephrologists report for delaying to tell patients about treatment options is the potential backfiring since serum creatinine levels occasionally fluctuate over time. Dr. Easton recounted how one of her patients was placed on the transplant waiting list and then was removed because her kidney function later improved. Similarly, if a patient is in a poor medical condition, Dr. Varga explained that he will concentrate first on dealing with their major medical problems before dealing with their dialysis, since the patient might die if the other medical problems are not controlled first.<sup>65</sup>

#### *policy factors*

The decision to wait to educate patients until their physiologic measures have reached a certain point might be in response to two policies. First, nephrologists may be taking into consideration the UNOS policy regarding eligibility for transplantation which requires patients to have a CC of 20 or less or to be already on dialysis. As presented above, nephrologists wait until patients' serum creatinine is about 5 or 6, which roughly corresponds to a creatinine clearance of between 20 and 25, to begin discussions about dialysis. It appears that nephrologists thus wait for patients to be eligible for transplantation to begin the education/referral process.<sup>66</sup> In other words, the UNOS policy may have a regulatory effect on the decision about the timing of education regarding treatment options and referral.

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<sup>65</sup> This practice reflects values of expediency and efficiency which are fundamental components of utilitarian approaches to resource allocation.

<sup>66</sup> Further research is required to assess the extent to which physicians practice medicine according to given medical guidelines.

Another policy that may reinforce the timing of education is a new guideline established for the timing of access placement. A pharmaceutical company and various experts in nephrology have drafted a guideline, called the Dialysis of Quality Indicator. According to the guideline, nephrologists should consider access placement when the serum creatinine is above 4. The basis of this recommendation is to allow each type of vascular access to mature. It takes 2 to 4 months for a native arteriovenous<sup>67</sup> fistula, and 1 month for an arteriovenous graft to mature. The guidelines recommend placing the access 12-18 months before nephrologists anticipate patients needing dialysis.

In sum, the initiation of discussions about treatment options is primarily based on the timing of a patient's referral to the nephrologist as well as the rate of progression of the patient's kidney disease. Early education (based on early referral) is clearly to a patient's advantage. Without the effects of uremia, patients can better comprehend their prognosis and treatment options to take better informed steps to prepare themselves for future changes in health and lifestyle, including getting listed for a transplant.

### **Order of Treatment Options Presented**

This part of the chapter examines how nephrologists decide in which order to present treatment options to ESRD patients. Presenting treatment options in a certain sequence constitutes a form of "framing" the options, with a possible (intended or unintended) effect of steering patients to one treatment over another. This section deals only with progressive patients since, by not having started dialysis, they have all options open to them for discussion with the nephrologist.

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<sup>67</sup> Arteriovenous fistulas are blood vessels made by surgically sewing together an artery and a vein. An arteriovenous graft is a form of vascular access made by connecting one end of an artificial vein to the patient's vein and the other end to the patient's artery (AAKP 1997).

The order of treatment options nephrologists present to patients with progressive renal failure generally begins with hemodialysis but the option discussed next is either transplantation or peritoneal dialysis. Nephrologists justified presenting treatment options in that order in similar ways. For instance, Dr. Ingel related, “Usually I discuss hemo first because ... when patients think of dialysis, most of them think of the kidney machine and so that’s what’s on the top of their mind when they discuss this.” Others noted that HD is the treatment that most patients are likely to receive first. For instance, Dr. Gilmore framed this in terms of statistics:

“I usually do it in the order that I think is the likelihood that they are going to end up on, just statistically, I mean 80% of ESRD patients are hemo, 15% are PD, and about 5% are transplant. So, when you look at it statistically, I usually do hemo first, PD, second, and transplant third. Not because I’m trying to give them any preferential order, but just statistically, that’s what I think they’re more likely to do and I think that they’re probably going to hear more about the first one. If I keep going on, option after option, they’re going to start *tuning you out* after a while. So I think since it’s the most likely statistically that they’re going to end up on hemodialysis, I want to make sure I cover that first *so they can hear me*” (emphasis added).

This excerpt points to a perception shared by most nephrologists in this study and other healthcare professionals that patients can grasp only a limited amount of information at a given time. Research has also shown this trend to be true (Ley and Spelman 1967). In their study of patient-physician communication, Ley and Spelman (1967:62-65) found that: a) the more information physicians present, the less patients recall, and b) patients tend to recall more information presented earlier than later in the consultation. These ideas are reiterated when Dr. Testa explained that for patients who are referred later in the course of their chronic disease, the discussion of treatments would not portray all options equally but rather focus on the “mechanisms of chronic dialysis therapy” in order to “let them digest what’s going on first.” In the next section, it will become apparent that this perception influences the extent of the information about each treatment option nephrologists present to patients.



Given the reasons offered, presenting the options in this order appears to maximize the efficiency of time spent during the clinic visit. In other words, by addressing hemodialysis first (because of the premises that most patients tend to start with it or think of it), nephrologists answer more questions earlier on in their discussion with patients. As the discussion progresses, there would be fewer questions since the explanation of hemodialysis has laid the groundwork for understanding PD.

### **Extent of Details Nephrologists Present about Treatment Options**

Do nephrologists provide different amounts of detail when discussing each treatment option? Doing so would constitute, in part, framing the treatment options. That is, the greater extent of information physicians present to patients about a given treatment may reflect partiality in favor of or against that treatment option. Depending on the content of the information given, the extent of it may influence (or steer) patients' choice of treatment. The extent of detail nephrologists reported to provide about treatment options depends on several interrelated factors, including, a) the patient's overall medical condition, b) how imminent the patient's renal disease is to becoming end-stage, and c) cues patients deliver and physicians pick up during their discussions of ESRD treatments. This section focuses on patients with progressive onset of kidney disease.

#### **Medical condition**

The extent of detail nephrologists provide about treatment options is influenced by the patient's medical status. If a patient has a comorbidity that needs to be addressed first, e.g., appendicitis or gall bladder removal, nephrologists wait for the patient to heal before focusing on the transplant option. In other words, nephrologists might say that transplantation is an option, but notify patients that there are considerable risks to undergoing transplantation without first

addressing patients' serious medical problems. To paraphrase what Dr. Nicola usually tells patients in such a situation:

"Transplantation is a wonderful option, the majority of patients do better and are better off with it, but it is not without risk, it is not a panacea. You need to be aware of the need to do a lot of testing, need to be seen by doctors frequently. But since you will not get a transplant for a while, let's discuss which dialysis modality you would like to live on for a while."

### Imminence of ESRD

Nephrologists tend to provide patients more information about their treatment options the closer patients' kidney disease is to becoming end-stage. New pre-ESRD patients are provided relatively few details about each of the treatment options. A typical conversation with pre-dialysis patients is about why renal failure is ultimately fatal, about symptomatology patients can anticipate, and treatment options. As Dr. Julian put it, "It's rare that in an initial meeting that [asking patients what renal replacement therapy they prefer] will come up. More often you present the options and allow the patient to think about it." Dr. Julian explained further how much information he provides to patients:

"The details I go into depend on how imminent the need for renal replacement therapy is. But I talk at least in a general way about dialysis versus transplant as two options. And again, depending on how close they are to actually needing it I will get into greater detail about the types of dialysis and about the types of transplants, about the outcomes, about how the two modalities compare in terms of patient survival."

Based on interviews with and observations of nephrologists, it appears that during visits early in the course of a patient's kidney disease, nephrologists inform patients of the general types of treatment options and how they can learn more about them. This limited discussion holds true for transplantation, as Dr. Easton noted, "I usually don't spend too much time discussing transplant. I'll give them the number to go and call. I'll say, this is one of your options, this is how you find out about it, this is what's involved."

Early clinic visits with patients with progressive onset are used to help patients become oriented to having ESRD rather than focusing immediately on treatment options. In the

following excerpt, Dr. Julian elucidates how nephrologists “psychologically prepare” patients by providing greater information over time, allowing each meeting to build upon the last:

“So those first encounters, generally they’re dealing with the reality of well, you have a disease that’s affecting your kidneys. The kinds of questions that come up in those early sessions is how did this happen, was it my fault, was it an infection, what did I do wrong, what can we do about it, what are the specific therapies, how can we prevent this from progressing. But even in the earliest sessions, almost always, if I understand that this is going to be a progressive and untreatable disease, almost always, we’ll mention at least the possibility that this can progress to terminal kidney failure and what the implications are in terms of death, dialysis or a transplant. But we’re not going to *overwhelm* a patient with a creatinine of 2, of those kinds of notions, so that’s where nephrologists play a role. We have the luxury of dealing with someone with progressive renal disease by meeting with them frequently and sort of *psychologically preparing* them for those issues, and with each session, the details become greater and greater. ... So it doesn’t all happen in one long term care session, it evolves with time in most cases” (emphasis added).

The limited extent of information and the psychological preparation nephrologists provide to patients early in their kidney disease is demonstrated well by looking at an excerpt from one clinical encounter between Dr. Easton and a pre-dialysis kidney patient with a low serum creatinine:

Dr. Easton explained to the patient, “Your kidneys are not functioning at 100% now. At your next visit we’ll look at it over time.” The patient said she thought her kidneys were not working because her friend asked her why she does not have to use the bathroom when they go out. Dr. Easton continued, “hypertension puts a load on the kidneys. *It’s not something to be worried about right now.* We’ll talk about it over time.” After the patient left, Dr. Easton told me, “She has a creatinine of 2.5. If I can get her hypertension under control, then it’s OK” (emphasis added).

This visit raises the question of whether a patient should be informed of potential future medical problems. The reason for not discussing the possibility of kidney failure and treatment options at that time is because the patient’s hypertension may come under control and delay the need for dialysis and thus the need to talk about it. By framing the kidneys’ status in a less threatening manner, e.g., the kidneys are not 100%, rather than saying that they are at 70% of functioning for example, Dr. Easton glosses over the issue of potential kidney failure. In this age of patients’ rights many patients expect to be informed of all aspects of their medical care. Given this context, it is surprising that relatively little information about the seriousness of potential kidney problems is imparted to patients. That nephrologists are reluctant to give probabilistic information about mortality rates of different treatments to patients supports this contention; this

issue will be discussed further below. Knowing more about potential problems may further motivate patients to alter their lifestyle to improve their health. While there are patients who trust their physician enough to stop being concerned after being told that their kidney problem is not something to worry about, there are others who are alerted by bodily changes and seek as much information as possible. Telling a patient to not worry may send the misleading message that no problems will occur in the future.

Nephrologists increase the frequency of office visits the closer patients' kidney disease is to becoming end-stage. The basis for doing this is to more closely monitor patients' blood chemistry levels to ensure proper timing of referral to dialysis. Not every meeting is directed at discussing treatment options. Rather, nephrologists and patients discuss uremic symptoms and blood pressure control and other ways of 'managing' patients' comorbidities. Yet the increased frequency of office visits leads to an increased likelihood of discussing treatment options. As Dr. Julian pointed out, "but almost always, long term treatment options creep into the conversation, and they do increasingly so as the patient comes closer to having true end-stage renal failure." Although treatment options are not discussed at every clinic visit, education occurs in a process that intensifies over time.

When discussing treatment options, nephrologists generally present information about their risks and benefits. An interesting feature of their discussions about risks and benefits is whether statistical information on the likelihood of survival of each treatment modality is presented or not. Such information can play a role in patients' treatment decisions. Nephrologists held different perspectives on informing patients of treatment survival rates. As Dr. Testa stated, he tends not to use statistical information unless he seeks to motivate someone to change their health behaviors. Instead he informs patients that the quality of life with a

transplant is better than dialysis and that the length of life is comparable with each modality. He does not present statistical data to help patients decide on a form of therapy because he considers it “a little badgering,” but will offer the data should someone ask for it. Similarly, Dr. Lock tends not to inform patients of how long they can expect to live on each modality because of the need to maintain patients’ “hope.”

“[Sighs. *Sotto voce*:] I don’t know, maybe I’m a liar. [Regular voice:] I just basically tell them that you know, if they’re compliant they can live on dialysis 3-4 decades. That’s not true. [EG: Do you have statistics that you know of in general?] Yeah, in general, there’s a 25% per year mortality in end-stage renal failure care on dialysis of both types. That means that every 4th patient I see is going to be dead next year... And it turns out that if you look at over 60 diabetic males, they will die faster than people with lung cancer. So some of it also depends on underlying disease. But if you are 25 and you have end stage renal failure, the chances are you will live 30 or 40 years if you are compliant on dialysis. So I tell that to the diabetic 65 years old. [EG: But you don’t want to tell them?] Well, it’s just a little different from oncology I think, my view. I’m not a real big one on taking away people’s hope. Now you could argue that by doing that, and putting more responsibility on them, so if they die they feel guilty because they weren’t compliant.”

The notion that revealing such numbers would undercut patients’ hope was also found in the study of oncologists by DeVecchio Good and colleagues, as presented earlier (1990:68, 1991). The oncologists believed that revealing numbers would also generate patients’ uncertainty and even undermine the patient-physician relationship, especially if the statistics were not good. Although nephrologists’ and oncologists’ reluctance to provide mortality statistics to patients is couched in terms of concern for patients’ hope, it is possible that this concern is a cover for their dislike or fear of discussing death, which has been shown to be quite common among American physicians (Ventres, et al., 1992; Stolman, et al., 1990; Taylor 1988).

In contrast, Dr. Julian presents some statistical information but allows patients to make their own interpretation of it.

“When I first deal with a new ESRD patient ... presuming that there are not absolute or strongly relative contraindications to transplantation, when I discuss the options for the patient, frankly, I point out something which is true, which is the data suggest that one’s chances of living longer are greater if one has a successful kidney transplant, as opposed to staying on dialysis, and that’s relatively new data. That wasn’t known to be the case say ten years ago, with the exception of living-related transplants where the data were clear that if you had a successful living-related transplant your own survival rate was higher than if you stay on dialysis. But it’s true now for cadaver transplants as well. So from that point of view, I tell patients that it’s a no-brainer, if you believe that statistics apply

to the individual, that if they want to live longer they should get off dialysis and have a transplant. The problem thereafter is the issue of what I call, 'tradeoffs.' If you opt for a transplant that's wonderful if it works. But the problem is one has to be a bit of a *gambler* because it might not work. And the reason why it might not work is, the reasons are several, but it might not work because of a surgical accident, it might not work more commonly because of your body's tendency to reject the kidney. Furthermore, even if you are a *gambler* and say 'I'll take my *chances*, I want that *chance* of a better survival with a transplant,' the problem is that we haven't perfected the drugs that prevent rejection. And the tradeoff comes in the sense of the patient having multiple side-effects, even fatal side-effects from the medications. *So when you put it that way*, a lot of patients are not interested in hearing about a transplant because they don't want to be *gamblers* and they're willing to make the presumption that statistics won't apply in their case and that they'll live forever on dialysis, and don't want to take a *chance* of doing something that might not work or more importantly, of taking a *chance* of dying from complications from immunosuppressant therapy" (emphasis added).

Here Dr. Julian uses the discourse of "gambling" and "chance" to help frame the risks and benefits of each treatment modality for patients. Yet these terms imply a random or "50-50%" likelihood of survival, despite statistical data showing that transplantation confers a greater patient survival than dialysis. When Dr. Julian says "So when you put it that way," he shows how he can frame his explanation of the risks and benefits of transplantation in a way that influences his patients' perceptions of transplantation and possibly even their willingness to undergo it depending on their personality as a risk taker.

A metaphor other than "gambling" may yield a different response from patients about choosing transplantation for three reasons. First, recall "prospect theory" as outlined in Chapter 1 which proposes that people are risk averse to gain and risk taking to loss. While patients gain a greater length and quality of life by transplantation than dialysis, by discussing transplantation as a heavily risky treatment through the discourse of chance and gambling, it is likely that patients will increasingly seek to avoid the risks. Second, patients may have different impressions about what it means to be a gambler; for some, it is an acceptable and enjoyable behavior, for others, it is seen as dangerous and even sinful. Third, six patients in this study voiced concern about getting a transplant because they want a "guarantee" that a transplant will work for them. However, statistics can never offer 100% certainty (Toumey 1996). Discussing transplantation's

risks and benefits as chance events highlights the uncertainty of them occurring and thus minimizes the perception of guarantee.

Further, statistical data apply to large groups of people rather than to individuals. However, patients may not know how to interpret statistical data, and as Dr. Julian notes above, some patients are “willing to make the presumption that statistics won’t apply in their case.” This trend has been found to occur in other cases (Toumey 1996). For instance, an anthropology of science study of public responses to fluoridating public supplies of drinking water found that despite substantial epidemiological evidence supporting its safety, a public counter argument mounted against it because public health professionals could not give 100% certainty of the benefits of fluoridation.

Patients in the study sample (n=4) and on the Internet (n=16) expressed both interest and reluctance in learning the mortality and life expectancy data for ESRD. This raises two important interrelated points, one pertaining to lay and professional’s interpretation of statistics, and one pertaining information-giving. Both dialysis professionals and patients rationalized the invalidity of life expectancy statistics through their understanding that age and comorbidities confound each patient’s likely life expectancy. Many patients provided rationales explicitly stating that these statistics do not apply to them for various reasons. For example, patients noted that the statistics were based upon the large proportion of elderly patients on dialysis. In addition, they noted that Internet users are generally higher educated and thus take better health care of themselves in contrast to the general ESRD population. Clearly, lay opinions about the relevance of statistics differ from professionals’ opinions.

The second important point is the fact that dialysis clinicians or physicians did not provide life expectancy information to patients who requested it.<sup>68</sup> This finding is supported by other studies (Beisecker and Beisecker 1990; Waitzkin 1985; Boreham and Gibson 1978) showing that patients desire more information than their physicians provide. Patients reported that their clinicians either simply did not know the data, or they found it difficult to pinpoint data given variation in patients' clinical conditions. In contrast, there were also patients who were highly reluctant to find out life expectancy data because of fear and denial that the statistics really apply to them. It is argued here that the rationalizations employed by patients and clinicians noted above contributed to what can be called a culture of silence regarding life expectancy data. This is another example of clinicians' attitudes about information-giving.

#### Cues and personality of patients

As noted in Chapter 1, information exchange between physicians and patients is an interactional process meaning that each party influences the other (Street 1991, 1992a,b; Waitzkin 1985; Roter and Hall 1992). This section briefly presents ways in which this interactional process influences the extent of information nephrologists communicate to patients about treatment options. Three nephrologists reported that they tend to discuss certain treatments more than others based on the cues they pick up from patients. It is likely, however, that patients respond according to cues provided in the nephrologists' presentation. For instance, Dr. Ingel notes that after describing both types of dialysis, a patient may respond, "well, I don't want that thing with tubes in my belly!" and Dr. Ingel would then leave PD as an option and move on to explain more about HD or transplantation. Dr. Ingel also tries to assess whether patients on

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<sup>68</sup> At least two people on the Internet and two people in the study asked me personally to provide them with the data, which I did after obtaining it from the Internet (see Appendix V).



dialysis, in their view, “appear to be doing most of the things in their lifestyle that they want to do.” Dr. Ingel explains how he makes this assessment in the following way:

“When I’m talking to individuals about whether transplant is a good option for them, one of the questions I ask them is, ‘Is there anything that you would like to do that you physically can’t do because you’re on dialysis or can’t do because of the time limitations you’re on dialysis?’ And a patient tells me, ‘You know, I’m doing everything I want to do, I’m not a traveler, I’d just as soon stay around here, I mean I have the energy to do things I want to do, I visit with my friends and I’m not really dissatisfied with my quality of life,’ that person’s not going to have a significant improvement in their quality of life<sup>69</sup> with a transplant.”

Dr. Easton similarly described how patients’ responses to her initial presentation of options serve as a guide for how she should proceed with the conversation:

“So, I just usually tell them early on about both things and we’ll talk about dialysis options as well. And then, you have a lot of people who just out right say, ‘No I don’t want that.’ Or some of them just don’t even want to talk about the whole process. It depends. It’s very different depending on the patient. Some patients attack it: some patients say, ‘Oh, I’m going to have renal failure in the next 50 years, how do we find out about a transplant?’ And then some people, they just disappear because they don’t want to talk about it.”

There is a stereotype among patients and clinicians about how some personality types correspond with the choice of ESRD treatments. Patients who seek a transplant (and PD) are seen as more independent and in control of their health or lives than those who remain on dialysis. The loose foundation of these stereotypes is that people who want a transplant usually want to resume control over their lives by eliminating dietary restraints and returning to work, among other ways (see Chapter 7). In contrast, patients who prefer to remain on dialysis tend to want other people to take care of them, rather than monitor their dialysis treatment themselves. These, of course, are very generalized sets of relationships and patients often have medical conditions (scar tissue in the stomach) or living circumstances (e.g., reside far from a HD or transplant center) that preclude them from seeking the treatment of their choice. There is a hint of these stereotyped patterns even in educational literature on ESRD for patients. One such guidebook (Life Options 1994) describes treatment options using the terms “control” and

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<sup>69</sup> It is interesting to note that in this example, it is the nephrologist rather than the patient who determines whether transplantation would significantly change the patient’s quality of life. Perhaps it is his medical training that leads him to think about patient treatment decision making in what some people might consider paternalistic terms.

“freedom,” and brief patient accounts about having one treatment or another use terms like “independence” and “passive.” More research, however, needs to be done on this issue.

Nephrologists and nurses sometimes help patients determine which option they should choose<sup>70</sup> by having patients tell them about their personality, lifestyle, and home life (e.g., being independent, fearful of relying on self for self-treatment) and then suggesting options that fit those traits. For instance, Dr. Julian asks some lifestyle questions relating to “how independent [a patient] wants to be,” “whether they feel like they want to manage their own health as opposed to allowing it to be managed by health personnel,” and “how much family support there is.” During a pre-dialysis education class, Joanne, a dialysis social worker, was asked by a patient “What is the easiest treatment to use” to which she replied, “It depends on the person. More independent people like PD because it is done at home or work...” A hemodialysis nurse likewise stated that she makes suggestions about treatment options based on the feel of the patient’s support system at home, and what the patient is leaning toward (based on their questions and comments) and discusses the options that seem relevant to their concerns. A study examining factors deemed important by patients, nurses, and physicians when choosing between hemodialysis and peritoneal dialysis found that patients placed a high value on independence while physicians placed a high value on the ability to work and travel (Groome, et al., 1991).

What is unknown, but must be considered, is whether other patient characteristics (e.g., socioeconomic status, education, ethnicity, gender) play a role in how extensively nephrologists discuss each treatment option. There may be subtle cues and communication styles between nephrologists and patients by virtue of their different backgrounds. This issue will be discussed further at the end of the section on education practices.

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<sup>70</sup> This practice is not the same as telling patients that they should seek a given treatment.

### **Encouraging Patients to Seek a Transplant**

Another aspect of communication is the level of encouragement one party conveys to another about a given issue. Encouragement can be defined as “giving support to” and “being favorable to” (Webster’s 1986). As such, encouragement is inherently a positive act. In this study, nephrologists may encourage patients to chose a treatment by recommending that the patient seek a transplant, e.g., ‘you *should* get a transplant’, or ‘a transplant is *good* for you because you are...’ In addition, encouragement may be expressed through enthusiasm, e.g., ‘transplantation is the best treatment for ESRD.’

As a communicative device, encouragement coincides with the “mutual influence” approach to studying communication, as outlined in Chapter 1. Nephrologists might frame their discussion of treatment options by encouraging patients to seek one treatment more than the other(s). The question this section aims to answer is, Are there certain patient characteristics which lead to greater nephrologist encouragement about kidney transplantation? Physician encouragement is important to consider because it can affect certain patients’ treatment choices.

The following presents nephrologists’ attitudes about encouraging patients to seek a transplant followed by patients’ assessments of their nephrologists’ level of encouragement and statistical analyses of these two factors.

#### **Nephrologists**

All of the nephrologists (n=12) reported that they generally encourage their patients to seek a transplant. Although nephrologists report supporting the concept of transplantation in theory, they are not proactive about encouraging patients to seek a transplant. For instance, Dr. Lock encourages patients by asking them “what’s your transplant status?” at every office visit.

She believed that doing so helps to “advance the cause a little bit more.” Dr. Olson described his way of encouraging patients to get a transplant:

“...I won’t actively say ‘I think you ought to get a transplant’ but most young people with primary renal disease who don’t have lots of other issues, I suggest it might be a worthwhile thing to think about transplantation. Just from a lifestyle perspective. It probably would simplify things for them.”

Dr. Olson’s comment reveals that he is not really encouraging unless the patient is young and/or in relatively good health. Although Dr. Olson’s manner of encouragement toward young patients is still relatively mild, other nephrologists openly report being especially encouraging to young patients and less so to older patients. The age-based encouragement practice is best described by Dr. Ingel when he said:

“But I do push, after having that discussion, a twenty-five year old tells me, ‘Well, I’m happy I’m doing things I want to do.’ I pushed them to at least get on the list. Whereas a sixty-five year old telling me that, I would not push them. And for people in-between there is kind of open depending on what their lifestyle is and physically what they’re able to do and how they’re limited.”

The lack of encouragement for elderly, yet still eligible, patients to seek a transplant can be illustrated well by looking at an excerpt from one clinical encounter between Dr. Julian and a 64 year old woman, Mrs. G, that occurred two months after she began dialysis:

Dr. Julian began the visit by asking her about transplantation. He asked, “You’re 64, has anyone talked to you about the possibility of the transplantation?” “I don’t think I could go through with it. Why do some people [who had a transplant] still need dialysis?” replied Mrs. G. Dr. Julian explained why in terms of kidney rejection. He then told her that he was not pushing transplantation for her because she is 64 and he didn’t want to ‘push’ the age limit, but noted that she’s not too old. He reasoned, “If you wait five years, till you reach 70, [to decide you want a transplant] then that’s pushing it. It sounds like if you want a transplant, you’d have to sign up for a cadaver donor.” He told Mrs. G that if she wants a transplant she’d have to go through “rigorous testing to see if you have a healthy heart.” He asked her “I don’t know if you’ve been told these options” to which Mrs. G replied, “you talked to me about it.” She told him that she didn’t want a transplant and that she’d rather “leave it for some younger person.” Dr. Julian commented that “the clock is ticking when you’re 64. Probably when I’ll see you [again] it’ll come up.” He also noted that “the process of getting tested does not commit you to get a transplant,” and that she would see a lot of different doctors in the evaluation process. “They all have different perspectives. I gather you’d like to sit with it. If you wait a few years and decide you want a transplant, you will be pushing it” he concluded. Mrs. G indicated that she was getting her strength back and had more appetite. Dr. Julian ended the visit by saying, “OK kiddo. This transplant stuff is open for discussion. You can call me about it anytime.”

In this encounter, since the patient was already on dialysis, the education discussion focused on kidney transplantation. This encounter shows how Dr. Julian informed Mrs. G of the

limited time she has to make a decision about transplantation due to her increasing age. While not necessarily encouraging, Dr. Julian expressed urgency for Mrs. G to make a decision before she gets too old for a transplant. Although Dr. Julian allowed the patient time to think about this option, he did not facilitate her decision making by asking about her disinterest in transplant. Had he asked why she did not want a transplant and why she believed kidneys should go to younger people, Dr. Julian might have clarified some misunderstandings and alleviated some of her anxiety. Instead he presented information that he believed would alleviate her concerns.

Let us deconstruct the beliefs informing their practices. The underlying assumption shaping nephrologists' age-based encouragement practices is that younger patients are healthier and thus better candidates for a transplant. Dr. Varga made this link clear: "I think the younger a person is, when I see them, I'll be more likely to encourage them. The healthier the person is." But because there are always exceptions to the rule, the definition of what counts as 'young' varies. In large part the exception is based on the patient's medical status. When asked to explain what counts as 'young,' Dr. Varga noted,

"I would say it's relative to a person's medical status. And young ... tends to go hand in hand with healthier also. So I would say young is teenage, because I don't see kids, but say teenage up to 40 for sure, unless it's a person who's very sick with diabetes and is 40 and blind and has amputations. Up to 40 and maybe up to mid-50s in someone who's medical problems are strictly related to their kidneys and not related to diabetes or severe hypertension or prior heart attacks, if they're doing pretty good in their overall condition, I'd extend that ceiling of age a little bit higher."

Two other nephrologists related their encouragement for young patients to seek a transplant to their underlying disease.

Dr. Julian: "Well, I think they should be biased, because if you were a diabetic with progressive renal failure and you were 30 years old, the data also suggest that you're going to live longer with a transplant. And so I bias them towards that as well. I think that that's the way that they should go if they want to live longer. So I don't think that's a bad thing, at least it's the right attitude to have."

Dr. Olson: "...If the people are young and have primary renal disease I really actively encourage them to do this. So if you have a 40 year old person who has no other disease who's on dialysis I'll go ahead and ask them if they're

interested in transplantation. If they say no, they'd rather not, I really explore that a lot more than I will with somebody who is 64 years of age who has diabetes who may have had peripheral vascular disease as well."

When patients express disinterest in a transplant, nephrologists encourage them to learn more about it by visiting the transplant center. Two nephrologists described their approaches to such patients in the following ways:

Dr. Nicola: "If patients say they don't want a transplant, I will encourage them to just go to the transplant center and at least visit and hear what they have to say about transplantation. That way they can learn what to expect and have a chance to ask questions. They don't have to go through with the surgery. But for people who are really not interested in a transplant, I don't force them."

Dr. Testa: "Yes. In the education process if they make a decision and it's founded in some sort of knowledge and they have a very good [reason]: '...I don't want to go through a transplant, I'm afraid of the medicines, and I can't ask anybody, I don't want to get a cadaver because I don't know where that patient came from,' I'll revisit that usually six months to a year after that decision. In fact, yearly we're required by law to ask the patient anyway, and I think that's a good law. Because people may have some fears that are inappropriate."

As these excerpts show, nephrologists believed that patients who do not want a transplant may be ill-informed, thus they encourage patients to obtain more information. It is possible that nephrologists perceive patients who do not want a transplant as 'irrational' because transplantation is understood to be a better treatment for ESRD. It has been noted elsewhere that patients "who refuse to accept professional recommendations will often have their mental competency challenged" in comparison to those who do comply (Guccione 1988:72 in Coy 1989).

Other nephrologists explained that while they encourage patients to seek a transplant, they also prefer not to influence patients' decisions. Neutrality in nephrologists' communication becomes apparent as Dr. Easton's comment shows:

"But by and large I think it's a patient choice. It's not really a doctor choice. I'm really against doctors making decisions for people. So I've put it out that it's like a buffet, and you choose what you want, here's what's possible. I always see myself as a resource like, if they come and they ask me, 'Hey doc, I've heard about this, this, and this, what do you think of this, what are the pros, what are the cons?' It's the same with choices between hemo and peritoneal. I try to give them a picture of what the risks and benefits are, what will be good, what will be bad, about all of it 'cause a transplant's not a panacea either. So, I'll usually tell them, 'Listen, you've been dealt a bad hand in life because renal failure is no fun no matter what it is, in how we treat it. And here is transplant, and this is what's good about it, this is what's bad. Here is hemodialysis, this is what's good, this is what's bad. Here is PD, this is

what's good, this is what's bad.' And I leave it to the patient to then make further investigation and decision. That's my style."

Dr. Julian pointed out that some doctors might be neutral in communicating treatment options because they are thinking ahead of time about a patient's comorbidities and might temper their discussion considering the patient's clinical situation. Based on their comments from interviews, it appears that nephrologists do not want to influence patients' choice of treatment, yet contradictorily, they provide young patients encouragement to seek transplantation. These two tendencies raise the questions: Why do physicians want to be unbiased in their presentation of options and thus not influence patients' choice of treatment? and, Why do physicians want to guide young patients to seek a transplant? We will address these issues at the end of this part of the chapter.

#### Patients' perceptions of nephrologists' level of encouragement

Patients' perceptions of nephrologists' level of encouragement may shed light on the manner and extent to which nephrologists actually are encouraging. There were significant relationships between some patient sociodemographics and their rating of nephrologists' encouragement level (see Table 6.1).

**Table 6.1 Patients' ratings of nephrologists' encouragement by patients' sociodemographics (n=77)**

Sociodemographics	n	Mean score	p-value <sup>1</sup>
Socioeconomic Status <sup>2</sup>			.001
SES level 1	1	5.00	
SES level 2	21	4.33	
SES level 3	16	4.06	
SES level 4	28	3.39	
SES level 5	11	2.64	
Cause of renal failure			.004
Hypertension	26	3.19	
Diabetes	23	3.39	
Glomerulonephritis	8	4.88	
Other	20	4.25	
Education			.010
Less than high school graduate	15	3.40	
High school graduate	22	3.14	
Some post-secondary	40	4.13	
Treatment Decision			.032
Pro-transplant	47	4.11	
Con-transplant	30	3.07	
Religion			.036
Protestant	60	3.45	
Catholic	11	4.64	
Other	6	4.50	
Employment			.040
Employed	26	4.19	
Not employed	51	3.45	
Ethnicity			.043
African American	51	3.47	
European American	22	4.27	
Age			.047
20-39	22	4.05	
40-59	37	3.73	
60+	18	3.22	

1. The significance is based on nonparametric correlations.

2. SES level 1 is high whereas SES level 5 is low.

As Table 6.1 shows, there were significant relationships between patients' ratings of their nephrologists' encouragement and patients' SES, education, etiology, ethnicity, religion, employment, and age (see Table 6.1).

Patients with higher SES levels rated their nephrologist's encouragement for them to get a transplant significantly higher than patients with lower SES levels. Since education comprises SES, it is not surprising that education level was also significantly related to ratings of



encouragement. Patients with more years of education rated their nephrologist's encouragement for them to get a transplant significantly higher than patients with less of education. Although there was a significant relationship between patients' education and ethnicity (See Table 7.2), the relationship between patients' education and their rating of their nephrologists' encouragement remained significant after controlling for ethnicity ( $r=.2304$ ,  $p=.051$ ,  $n=73$ ).

Patients rated their nephrologists higher if their ESRD was caused by glomerulonephritis or other factors than by hypertension and diabetes. When controlling for ethnicity, the relationship between etiology and encouragement remained significant ( $r=.2283$ ,  $p=.054$ ,  $n=73$ ), thus indicating that ethnicity had little to do with the relationship. It may be the case that patients with glomerulonephritis tend to be healthier than those with hypertension or diabetes and thus are encouraged more so to get a transplant.

European American patients rated their nephrologist's encouragement for them to get a transplant on average significantly higher than African American patients. This relationship was no longer significant after controlling for both treatment decision ( $r=.1911$ ,  $p=.108$ ,  $n=73$ ) and education ( $r=.1557$ ,  $p=.191$ ,  $n=73$ ). This suggests that ratings of encouragement were confounded by the facts that: a) European Americans had significantly higher education levels than African Americans and, b) more European Americans than African Americans tended to favor transplantation, as will be discussed in Chapter 7.

Patients who were of Catholic and other religious backgrounds rated their nephrologists' encouragement significantly higher than those who were Protestant. When controlling for ethnicity, the relationship between religion and ratings of encouragement was no longer significant ( $r=.1796$ ,  $p=.131$ ,  $n=73$ ). This suggests that ratings of encouragement were confounded by significant ethnic differences in religion (see Table 7.2).

Patients who were employed rated their nephrologist as more encouraging than unemployed patients. This finding may be related to the trend for employed people to be generally healthier, thus, nephrologists would encourage healthier people more so to seek a transplant.

Younger patients rated their nephrologist's encouragement for them to get a transplant higher than older patients. However, when controlling for treatment decision, the relationship between age and ratings of encouragement no longer emerged ( $r=.1047$ ,  $p=.368$ ,  $n=77$ ). This finding may be due to the fact that age and treatment decision are significantly related (see Table 7.2), and shows that treatment decision is significantly related to ratings of encouragement.

Of the patients who responded to this question, pro-transplant patients rated their nephrologist's encouragement for them to get a transplant on average significantly higher than con-transplant patients. This relationship remained significant even when controlling for age, education, SES, and ethnicity. This relationship may be due to the fact that patients seeking a transplant are more enthusiastic about discussing transplantation than patients not seeking a transplant. Consequently, their enthusiasm may have facilitated greater discussion with their nephrologists about transplantation.

Of the patients who received encouragement, fourteen patients stated that their nephrologist was very encouraging for them to get a transplant because they were young. While over twice as many of these patients were male and in favor of transplantation, they were evenly divided by ethnicity. Patients conveyed how their nephrologists expressed encouragement to seek a kidney transplant in the following ways:

Scott: "[The Doctor said] I'm a perfect candidate for it, I'm young, it will last a lot longer."

Donna: "He thought I was a good candidate, I am young, there's nothing else wrong with me, he thought I had a good chance with a transplant."

Eight patients reported that their nephrologist had encouraged them to get a transplant because they were relatively healthy. While the majority of these patients were male, half were African American, (three were European American), they were evenly divided by transplant status. For instance, as Michael noted, “Dr. Gilmore wanted me to get one because I’m really healthy.” (His proof was his stomach rivets -- highly formed stomach muscles showing strength. Dialysis patients who do not feel well tend not to exercise and develop strength.)

A number of patients (n=19) said their nephrologist encouraged them to get a transplant because of what he or she told them. Six of these patients reported that their doctors told them that they *should* get a transplant. For instance, one patient (Arthur) recounted his nephrologist saying that he should go to the transplant center and find out if he could be a candidate. Another six patients reported that their doctors said that their lifestyle would improve following the transplant. As Fatima noted, Dr. Julian really wanted her to get a transplant because “life will get back to normal and I can eat whatever I wanted.” Three of these patients were encouraged by virtue of their nephrologists having discussed transplantation as a possibility. As Georgia stated, “she talked to me all the time... they’re always encouraging you.” Two of these patients who had the same doctor (Talmadge, Gina), considered Dr. Gilmore encouraging because he explicitly told them that they *needed* to get a transplant. According to Talmadge, “Dr. Gilmore said it was necessary. Just point blank: your kidneys are going to fail and you’re going to need a new kidney.” Two other patients (Cecelia, Irving) considered their nephrologists encouraging because they expressed a highly positive attitude about transplantation.

Conversely, con-transplant patients rated their nephrologists on average, as significantly less encouraging to get a transplant than pro-transplant patients, as noted above. The question this relationship raises is similar to “Which came first, the chicken or the egg?” It is unknown

whether the lack of nephrologist encouragement influenced patients to not seek a transplant, or whether patients' disinterest in transplantation influenced nephrologists to not try to encourage patients to seek a transplant. Patients' comments seem to support the latter interpretation. One reason nephrologists may have come across as not encouraging is because some con-transplant patients (n=3) (2 inadvertently, 1 intentionally) stopped them from discussing transplantation any further after they had brought it up. As Clifford stated, "[My nephrologist] gave me options. I stopped him right there" [because I did not want a transplant]. All of these patients were over age 50.

Among the group of patients who received little or no encouragement from their nephrologists, a theme emerged in which six patients interpreted this as the nephrologist letting patients decide about transplantation on their own. Patients' statements to this effect are as follows:

Andrew: "He never tried to impose his will on me or anything... He just mentioned it [transplantation] to me."

Sofia: "[the doctor encouraged me] to go to the transplant center, she gave me her opinion but didn't force me. She left it up to me."

Virginia: "[Dr. O was not encouraging,] not one way or another, like it was my decision."

Patients did not comment on whether or not they appreciated the lack of encouragement from their nephrologist. The majority of the patients who expressed these views were con-transplant patients.

The comments from both pro-transplant and con-transplant patients suggest that physicians and patients read cues regarding each other's interest in transplantation as a basis for deciding whether to engage in further discussion about it.

There were no significant relationships between perceptions of encouragement and the particular AH nephrologist being rated (n=63). This suggests that all nephrologists equally

encouraged (or neutrally discussed transplantation with) their patients to the same extent. In sum, these data suggest that, from a patient's perspective, nephrologists were somewhat biased in their level of encouragement when discussing transplantation with people of different sociodemographic backgrounds.

### Synthesis of encouragement practices

Having examined both nephrologists' encouragement patterns and patients' perceptions of encouragement, we can draw several conclusions by further deconstructing the moral values informing their decisions. According to both the physician and patient interviews, nephrologists seem to strongly take age into consideration in the emphasis they placed on transplantation as a viable treatment option. This may reflect an "efficiency" model underpinning their emphasis on age. This means that there is a preference to allocate scarce resources to people who can obtain the greatest use out of them. The 'greatest use' is interpreted in terms of the number of years a patient can use a kidney graft, and the corresponding sociodemographic variable is age. Younger patients can live longer than elderly patients so there is a better chance of a graft surviving in someone who is likely to live a long time, instead of being cut short by the death of the recipient.<sup>71</sup>

Another way nephrologists could or do potentially interpret 'greatest use' is in terms of quality of life. The quality of life of transplant patients has been shown to be better than that of dialysis patients. Given this distinction, it would make sense for nephrologists to not focus on a sociodemographic variable like age since people of any age could greatly enhance what the transplant professionals consider as their quality of life by obtaining a transplant. The question

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<sup>71</sup> The 5 year graft survival rate is 79.9% for CAD and 76.3% for LRD; the longest living recipients of a CAD and LRD respectively, are 31 years and 29 years (HCFA 1997:5).

becomes, should a sociodemographic variable be used as a proxy of quality of life? It would not be income, nor education, sex, ethnicity, etc.

Bioethicists contend that society's approach to death and dying is embedded in a utilitarian approach (Jackson 1994; Thorson 1978). Based on the data presented above, the same can be said about allocating kidneys for transplantation. Utilitarians decide what the right course of action is based on calculating what maximizes benefit. As Jackson notes, however, "the practicalities of calculating utility are often at least as problematical as those produced by trying to decide priorities by comparing needs and the ends to which they are relevant" (1994:92). Nephrologists' encouragement practices therefore appear to be a form of framing information. By encouraging younger patients to seek a transplant and by being neutral about it to most others, nephrologists seem to be enacting a utilitarian approach to allocating scarce resources. In this way, they may be acting as a subtle gatekeeper to the transplant center.

### **Discussion**

In the first half of this chapter we have found several patterns of information-giving among nephrologists in this study. First, nephrologists provide information about treatment options over time for progressive patients or wait until patients become stable in emergent cases. Second, nephrologists present treatment options in the order of dialysis then transplantation. Third, the extent of information-giving relates to: a) the patient's medical condition, b) how imminent renal disease is to becoming end-stage, and c) cues of patients. Fourth, nephrologists encourage younger and healthier patients to get a transplant, but tend to be neutral in their information-giving about treatment options overall. What do these patterns mean? Are nephrologists steering patients? Are nephrologists acting as a gatekeeper? Let us now analyze the implications of each practice in turn.

First, why is the educational process progressive with patients whose kidney disease is becoming end-stage? A cultural constructivist interpretation of nephrologists' information-giving practices is useful because it accounts for respondents' actual experiences of communication with patients rather than imposing a theoretical construct not grounded in ethnographic evidence. The primary reason for engaging in this medical practice pertains to a cultural understanding of "information." The nephrologists in this study implicitly viewed information as that which "overwhelms" and causes anxiety. Thus, nephrologists educate patients over time rather than during one clinical encounter in order to not overwhelm patients with all of the information at once. Yet regardless of interpretation, patients do not receive all the treatment information early on even though they will need it to make treatment decisions in the near or distant future.

Traditionally, physicians in the US have maintained a paternalistic approach to information transfer: they withheld information because of their assumption that patients could not understand the complexities of medical diagnoses and treatment (Katz 1984). Research in the 1970s found that patients were dissatisfied with the amount of information they were receiving. Since then investigators have sought to provide patients more information with the understanding that patients will be less anxious over a feared event when given objective factual information about it (Teasdale 1993).

Despite this trend in medicine, studies continue to report that physicians (e.g., oncologists) explain aspects of treatment options progressively, throughout the course of a patient's treatment because of the concern with overwhelming patients as in the case of breast cancer in the US (Freidson 1970; Mathews 1983; Rittenberg 1985; DelVecchio Good 1991). Oncologists in the US believe that disclosing information to patients about terminal prognoses of

cancer will cause them to lose hope and the will to survive. The fact that the nephrologists shared oncologists' notions about the importance of hope lends further validity to this cultural analysis of biomedicine.<sup>72</sup>

We can problematize nephrologists' information-giving practices further by considering alternative perspectives. There are two different ways of defining "information" depending on whether the person making the distinction relates to those in a position of seeking power, e.g., patients, or to those in a so-called position of power, e.g., physicians. Those who sympathize with the role of patients define "information" as "that which removes or reduces anxiety" (Attneave 1959 in Waitzkin and Stoeckle 1972:190). This definition may seem idiosyncratic, but the basis for it is the understanding that acquiring knowledge helps to alleviate uncertainty about one's medical condition. In addition, it has been argued that "information itself yields power" (Waitzkin and Stoeckle 1972:189). Information is considered power because increased knowledge helps patients make choices that best coincide with their own values rather than allow others (physicians) to make medical choices about their lives. Those sympathetic with the patient's perspective view withholding information as a form of social control (Zola 1972). This perspective, however, probably represents the values of patients of European rather than of other ethnic heritages who do not necessarily wish to be informed of their diagnosis or prognosis (see Frank, et al. 1998).

This last point leads us to ponder whether nephrologists' progressive manner of information-giving constitutes a form of social control over patients, as some critical medical anthropologists such as Marxists may contend. As noted in Chapter 1, Waitzkin (1985)

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<sup>72</sup> Oncologists in Italy also engage in this practice (though it is changing) of withholding information about the diagnosis of cancer because of the assumed need to maintain hope (Deborah Gordon 1990, 1994). The fact that oncologists in the US and Italy engage in this practice may reflect either similar cultural values of hope embedded in biomedical theories in both countries, or a broader belief system pervasive in Western Biomedicine in general.



considers withholding information a way for physicians to exert their power in situations of uncertainty. There is no evidence suggesting nephrologists' desire to control patients, but rather to control the disease. The latter view is plausible since some patients have reversible kidney damage early in their diagnosis, but it is difficult to predict who will experience this and when it will occur. Uncertainty about whether or not patients' renal disease will evolve into renal failure may explain why nephrologists tend to wait to inform patients of their treatment options until their renal failure becomes imminent. Other research likewise shows that physicians' uncertainty about the prognosis of cancer affects the extent of information they present to patients (Amir 1987).

Turning to the next pattern, presenting the treatment option of hemodialysis before transplantation requires further consideration. Nephrologists explained that they presented options in this order because it coincided with the likelihood of patients actually obtaining those treatments. This practice may inadvertently guide some patients to consider hemodialysis more seriously than transplantation. The relationship between order of presentation and steering is made apparent by turning to the older but significant study of patient-physician communication by Ley and Spelman (1967:62-65), presented earlier in the chapter. Given their finding that patients tend to recall more information presented earlier than later in the consultation, we might expect nephrologists to present transplantation first because patients would remember it more than dialysis and it is the most medically- and cost-effective treatment for ESRD. Professionals in the US usually cover the more important issues up front when communicating for emphasis (e.g., in media, literature, etc.). If nephrologists discussed living-donor transplants initially, for instance, perhaps more patients with progressive renal disease would be able to secure a living donor transplant before their kidney disease becomes end-stage.

Nephrologists present greater information about treatment options to patients who are medically stable and whose renal disease is close to becoming renal failure. We have lightly touched on these issues above, notably, the concerns about overwhelming patients with information when they are not ready to absorb it because of their clinical situation, and the concerns about informing patients when they might have reversible kidney disease. Other research has likewise found that physicians vary their information-giving according to differences in patients' medical condition (Beisecker and Beisecker 1990). The issue we have not yet addressed is the role of patients' cues in nephrologists' information-giving.

Three nephrologists reported that they relied on cues from patients to guide the amount and type of information they gave patients. In addition, during interviews nephrologists used examples that reflected their responsiveness to patients' verbal expressions. As discussed in Chapter 1, physicians are more likely to provide information to patients who are more expressive during the clinical consultation, and such patients tend to be of higher socioeconomic status. This study did not set out to directly test whether nephrologists perceive socioeconomic differences in their patient population, and whether these differences influence nephrologists' decisions about when and how extensively they should provide information about treatment options to patients.<sup>73</sup> However, in most cases, there are clearly major socioeconomic differences between ESRD patients and nephrologists since the majority of the ESRD patients in general are unemployed, have a considerably lower income than physicians, have less education than physicians, and are elderly.

In addition, in this clinical context, most (4 of 5) nephrologists were European American while the majority of patients were African American. Given that problems in physician-patient

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<sup>73</sup> Methodologically, the patients who were randomly observed during clinic visits were not tracked.

communication have been found when there are significant socioeconomic differences between patients and practitioners, it is likely that communication problems also occur between ESRD patients and nephrologists. Evidence from other research shows that nephrologists' communication practices are influenced by the socioeconomic backgrounds of the patients. A study designed to assess the impact of patient medical and sociodemographic variables on renal health professionals' recommended treatment choices used a mailed survey of 18 written case vignettes describing new ESRD patients (Deber, et al., 1985). The sample consisted of 30 nephrologists and 27 renal nurses and technicians. The study respondents were not in consensus about appropriate treatment for ESRD. Age had a highly significant effect on suggesting treatment choice: young patients were thought to be more suitable for transplantation, and clinicians were more inclined to recommend in-center mode of dialysis for older patients. Respondents were also more reluctant to transplant a hypothetical patient whose intelligence was borderline.

Lastly, we turn to the issue of nephrologist encouragement of transplantation as a treatment option for ESRD. Nephrologists reported that they encouraged younger and healthier patients more than older patients to seek a transplant. These two patient characteristics may count as patient "cues" discussed above. While younger and healthier patients may benefit from physician encouragement and thus be more inclined to seek a transplant, patients who do not fall into this category are at a disadvantage. This practice constitutes a clear example of steering. Earlier in the chapter nephrologist encouragement was examined in light of the utilitarian view that nephrologists appear to prefer that kidneys go to those who could 'best' use them. Patients who can 'best' use kidneys are assumed to be those who have the least likelihood of wasting them by dint of their relatively good health and a record of compliance behavior. In this regard,

we might find that nephrologists maintain a very subtle form of gate-keeping in referring patients to the transplant center. This will be explored further in Chapter 9.

These patterns about nephrologists' communication practices are contrary to expectation of this study in several regards. Overall, the nephrologists seemed neutral in the nature of their communication about treatment options to patients. This is unusual for three reasons. First, transplantation is commonly accepted in the dialysis and transplant community as a better treatment for ESRD than dialysis. It was therefore expected that nephrologists would be more involved in patients' decision making (e.g., giving directives to patients to get evaluated at the transplant center), but they did not.

Nephrologists' resistance to using life expectancy statistics to emphasize the superiority of transplantation is unusual and this practice can be considered another aspect of their neutrality in information-giving. There is a trend in American biomedicine to rely on objective measures, e.g., probabilities or statistics, to estimate the *success* of given treatments (Poses, et al., 1989; Nakao and Axelrod 1983; Christensen-Szalanski and Bushyhead 1981) but not to show high mortality rates. Even transplant surgeons in this study relied heavily (even almost entirely on statistics) to inform patients of the risks and benefits of kidney transplantation. The calculation of probabilities to assess the likelihood of uncertain outcomes can even be considered a Western form of reasoning (cf. Quinn 1978).

Nephrologists' neutrality or lack of involvement in patients' treatment decision making can be deconstructed in light of several biomedical and bioethical values. First, this practice coheres with efforts to respect patient autonomy by not interfering with patients' decisions. Studies have similarly found that other healthcare professionals are neutral in the information

they provide about certain treatments in order to respect patient autonomy, suggesting a shared value within biomedicine (Bosk 1993; Makoul, et al., 1995).

Nephrologists' neutrality and lack of involvement in patients' decision making differs from the traditional physician-patient relationship characterized as "Guidance-Cooperation" whereby physicians are expected to give directives for treatment and patients are expected to comply (Szasz and Hollender 1956). Although the traditional physician-patient relationship has received much scrutiny because of its inherent paternalism (Emanuel and Emanuel 1992; Blustein 1993; Veatch 1984), there is substantial evidence showing that physicians continue to give directives to patients about treatment in clinical encounters (Makoul, et al., 1995; Street 1991, 1992a,b; Stiles and Putnam 1992). In fact, "the failure to offer a prescriptive recommendation concerning treatment [e.g., for a cholesterol count of 350] would probably be seen as grounds for a malpractice charge due to culpable negligence" (Caplan 1993:152). Physicians even provide treatment recommendations framed in such a way as to persuade patients to comply with their goals (Kayser-Jones 1995). Some bioethicists argue in favor of physician involvement in patient's decision making because the "transforming effects of illness" put constraints on patient autonomy and it is the physician's role to restore patient's capacities for autonomous choice (Ackerman 1982:14; Thomlinson 1986; McCullough and Wear 1985; Pellegrino 1984).

Bioethicist Arthur Caplan (1993) considers the ethos of neutrality to be equated with nondirectiveness among genetic counselors. Genetic counselors engage in nondirectiveness in order to communicate and convey information effectively with clients, which means listening carefully and avoiding direct challenges or confrontations with clients. He argues that nondirectiveness is not a value-neutral practice. Rather, it is based on values of respect for

patient autonomy, and of informed decisions to be made without experiencing information overload.

These unusual circumstances of nephrologists' communication practices suggests that they might be experiencing a conflict of interest. There are several explanations of nephrologists' apparent neutrality. First, nephrologists may not want to lose patients to transplant surgeons by communicating positively about transplantation. In other words, nephrologists may have a financial incentive to not speak highly of transplantation, especially in the context of minimal capitated reimbursements from Medicare.<sup>74</sup> Since nephrologists receive capitated payments per patient, they may try to maximize the number of patients in their clinic schedule to maximize their reimbursement (see Abraham 1993).

The second reason pertains to how the clinical context, as noted in Chapter 1. In their clinics, nephrologists had busy case loads and often fell behind in their schedules. A busy case load meant that there was less time for discussion.

Lastly, nephrologists may believe that not every patient should get a kidney transplant because the waiting list is already too long. Nephrologists, among other transplant professionals, are highly aware of the scarcity of organs and may act as gatekeepers in letting patients get onto a transplant waiting list. Bioethicists have commented that should transplantation efficacy increase, then physicians will increase their referrals of patients to transplant centers (Robertson 1989). This suggests that the status of scarcity of organs affects nephrologists and reinforces their role as gatekeepers. This finding is similar to the case of genetic counselors who maintain neutrality in discussions of treatments to conserve scarce resources (Bosk 1993). As will be

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<sup>74</sup> This debate will be discussed further in Chapter 8.

shown in Chapter 9, while nephrologists report that they always refer patients to transplantation, there is some evidence to the contrary.

In this chapter we have covered one major area in which nephrologists may influence patients' access to transplantation: the information-giving about treatment options for ESRD. Both medical and nonmedical patient factors, e.g., age, appear to play a role in nephrologists' decisions about information-giving. These decisions, it is argued, are likely to effect patients' treatment decisions. The next chapter examines many factors that inform patients' treatment decisions.

## **CHAPTER 7: PATIENTS' TREATMENT DECISION MAKING FOR ESRD**

In previous chapters we have established a foundation for understanding ESRD, treatments for it, patients' experiences of dialysis, and the nature of information about treatments given to them by nephrologists. In Chapter 6, we examined how dialysis professionals communicate with patients about their treatment options for ESRD, and deconstructed the cultural values informing their decisions. Once patients learn about their options, they must make a decision about which treatment to seek. This chapter examines the central theme of this research -- patients' treatment decisions and influences upon them.

The focus will be on how patients decide which treatment to select. We will continue to use cultural constructivism as a tool for deconstructing the social, cultural, and economic values and factors that inform patients' decisions to select one treatment over another. The existence of such factors is important because it can help explain differences in access to transplantation among various populations.

This chapter covers a broad range of issues involved in patients' treatment decision-making process. 1) It begins by summarizing the sociodemographic profile of all patients included in this study, and then compares the profiles of patients within the two treatment groups. 2) We then assess the reasons why some patients have chosen transplantation or to remain on dialysis for treatment. 3) What follows is an account of how other people (e.g., healthcare professionals, family, and kidney recipients) and financial issues influence patients' decisions. A key component of this chapter involves deconstructing how ethnic identity and sociocultural values inform patients' treatment decisions.



## SOCIODEMOGRAPHICS AND CLINICAL DEMOGRAPHICS

### Sociodemographic Summary of Study Patients

An examination of selected sociodemographic and clinical characteristics of hemodialysis patients (n=79) reveals that the study population (randomly selected among eligible patients) is almost evenly divided by gender (40 females and 39 males). The study population is largely middle aged, the mean age was 47.9 years, with a range of 19 to 73 years of age, spanning 54 years.<sup>75</sup> Patients completed a mean of 13 years of education; 81% had at least a 12th-grade education. With regard to marital status, 30.4% were single, 32.9% were married, 26.6% were divorced or separated, and 10.1% were widowed.

The population consisted of 51 African Americans (67.1%), 24 European Americans (30.4%), 2 Jamaicans (2.5%), 1 Middle Easterner (1.3%), and 1 Asian patient (1.3%). Most patients were native to Cleveland or Ohio (n=52). Sixteen African Americans were originally from Southern states; they generally came to Cleveland as babies or youths (n=6) or in their mid-teens (n=10). Two African Americans were originally from the Northeastern state of Pennsylvania. Eight African Americans noted having mixed ancestry with Native Americans.

The European Americans were of diverse ethnic backgrounds, including: Western European descent (n=13), Eastern European descent (n=6), and Mediterranean descent (n=5). Few were originally from other regions of the country, including the Northeast (n=3), Midwest (n=1), and Western Plain (n=1).

The majority of patients (n=61) (77.2%) were of Protestant denominations, with Baptists composing 67.2% of them. Twelve patients (15.2%) were Catholic, and six patients (7.6%) were

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<sup>75</sup> The average age of the study population is considerably lower than the average age of new Medicare enrollees in 1987, which was 56.9 years (Eggers 1990). This difference may be due to the fact that only patients who were eligible for a transplant were included in this study, and the likelihood of eligibility decreases as people age.

of different religions, including: Jewish (n=2), Muslim (n=2), Greek Orthodox (n=1), and Metaphysics (n=1).

One-third of the patients were employed: 20.3% worked full-time and 10.1% worked part-time. Patients reported employment in service (n=9), professional (n=8), business (n=4), and labor (n=3) occupations (see Appendix VII for a list of positions under each occupation category). Patients were unemployed due to being: a) disabled (n=27) (34.2%), b) students (n=3) (3.8%), and c) retired (n=25) (31.6%). Patients' (n=69) incomes ranged widely; median income was \$8,400.<sup>76</sup> The majority of the sample (60.9%) had incomes less than \$10,000, whereas 23.4% had incomes between \$10,000 and \$25,000, and 15.6% had incomes greater than \$25,000. Medicare was the primary source of insurance for 51.9% of patients and Medicaid the secondary source of insurance for 31.6% of patients.

Patients were classified into five socioeconomic status categories that may be comparable to upper class, upper middle class, lower middle class, upper lower class, and lower lower class (according to the Hollingshead index, see Chapter 2). The breakdown was as follows: level 1 (highest SES) (n=1), level 2 (n=22), level 3 (n=17), level 4 (n=28), level 5 (lowest SES) (n=11).

The three most common causes of kidney failure were hypertension (32.9%), diabetes (31.6%), and glomerulonephritis (10.1%). The number of years on dialysis ranged widely among the sample population. The shortest and the longest length of times on dialysis at the time of the

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<sup>76</sup> Patients' annual income was calculated based on multiplying their monthly income by twelve because many patients could not recall their individual annual income since they were on disability. For purposes of statistical analyses, patients' incomes were grouped into three categories used by Bame, et al., (1993:1036). They operationalized income levels according to family income in the previous year in the following way: low income is less than \$10,000; medium income is between \$10,000 and \$25,000; and high income is greater than \$25,000. Fifteen patients' incomes were not factored into the analyses because six patients did not wish to disclose their income, five did not know their income, and three provided family incomes, and one did not specify the exact amount. The median is used here instead of the mean because the distribution of incomes was right-skewed due to the fact that most patients were unemployed and had small incomes.

initial interview were, respectively, less than one month and 17 years. The median and mode of time on dialysis was one year.

### **Sociodemographic Differences Between Pro-Transplant and Con-Transplant Patients**

At the outset of the study period, thirty (38.0%) patients chose to remain on dialysis, and forty-nine (62.0%) patients had chosen transplantation as their desired treatment modality. A number of patient factors (demographic and clinical) are related to patients' treatment decisions see Table 7.1. Older patients were significantly more likely to remain on dialysis than to seek transplantation as a treatment modality ( $t = -2.999$ ,  $p = .004$ ). Significantly more patients who chose dialysis were divorced, separated, or widowed than those who chose transplantation ( $X^2 = 18.977$ ,  $p < .0005$ ). The relationship between treatment choice and marital status may be confounded by age. This relationship may be due to the fear of seeking a transplant without aid and support from kin. There were no differences in patients' treatment choice by gender, years of education, employment status, income, SES, and geographic origin within the US.

**Table 7.1 Sociodemographics of two treatment groups, N (%)**

	Pro-Transplant	Con-Transplant	Significance <sup>1</sup>
Number (%)	49 (62.0%)	30 (38.0%)	
Mean Age	44.61 years	53.37 years	p=.004
Gender			N.S., p=.248
Female	22 (44.90%)	18 (60.0%)	
Male	27 (55.1%)	12 (40.0%)	
Ethnicity			p=.129*
European American	18 (36.7%)	6 (20.0%)	
African American	28 (57.1%)	23 (76.7%)	
Jamaican	1 (2.0%)	1 (3.3%)	
Middle Eastern	1 (2.0%)	0	
Malaysian	1 (2.0%)	0	
Education			N.S., p=.215
Mean grade	13.34	12.57	
Marital Status			p<.0005
Single	19 (38.8%)	4 (13.3%)	
Married	21 (42.9%)	6 (20.0%)	
Separated/Divorced	7 (14.3%)	14 (46.7%)	
Widowed	2 (4.1%)	6 (20.0%)	
Religion			p=.011
Protestant	33 (67.3%)	28 (93.3%)	
Catholic	12 (24.5%)	0	
Other	4 (8.2%)	2 (6.7%)	
Original Disease			p=.044
Hypertension	11 (22.4%)	15 (50.0%)	
Diabetes	18 (36.7%)	7 (23.3%)	
Glomerulonephritis	4 (8.2%)	4 (13.3%)	
Other <sup>2</sup>	16 (32.7%)	4 (13.3%)	
Years on Dialysis	1.58 years (mean)	3.66 years (mean)	p=.004
Employed			N.S., p=.324
Yes	17 (34.7%)	7 (23.3%)	
No	32 (65.3%)	23 (76.7%)	
Average Income	15,510	11,648	N.S., p=.264
SES Categories			N.S., p=.176
Level 1 (highest)	0	1 (3.3%)	
Level 2	16 (32.7%)	6 (20.0%)	
Level 3	12 (24.5%)	5 (15.7%)	
Level 4	17 (34.7%)	11 (36.7%)	
Level 5 (lowest)	4 (8.2%)	7 (23.3%)	
Primary Insurance			N.S., p=.323
Medicare	23 (29.1%)	18 (22.8%)	
Medicaid	9 (11.4%)	3 (3.8%)	
Secondary Insurance			N.S., p=.329
Medicare	11 (13.9%)	4 (5.1%)	
Medicaid	14 (17.7%)	11 (13.9%)	

1. N.S. means "not significant."

2. Other diseases include: lupus (n=6), various other diseases e.g., benign tumor (n=5), cystic kidney disease (n=4), interstitial nephritis (n=3), hereditary disease (n=1), and unknown cause (n=1).

\* This statistic is based on a comparison between African Americans and European Americans.

This study examined patients' treatment decisions according to ethnic identity and other categories of social identity. On the one hand, some statistical analyses use the same ethnic categories as does the clinical literature because of the limited number of patients within different ethnic groups in this study. On the other hand, this study shows that other sub-cultural groupings are equally, if not more, salient in patients' treatment decisions. This approach allows us to move beyond the potentially harmful process of essentializing people's behaviors.

Before presenting statistical analyses comparing the treatment decisions among different sub-cultural groups of patients, it is instrumental to introduce background information on various ethnic groups' values that may inform their approaches to resolving biomedical issues particularly, transplantation. This background information will serve as context for interpreting both the qualitative and quantitative analyses on treatment choices. Because ethnic identity can be based on religious affiliation, contextual information about ethnic and religious groups is presented together below. Only those groups represented by the study sample will be discussed. The ethnic identity of different non-African Americans is discussed by way of religious groups since the degree to which patients adhere to their cultural heritage has not been assessed.

Therefore, the statistical comparisons will be made between either African Americans and European Americans and/or African Americans and Americans of Western European, Eastern European, and Mediterranean descent. Since there are too few patients in the study sample to perform statistical analyses among various sub-cultural groups, most analyses reported here will be between the first ethnic grouping of patients.

It must be pointed out that the social science and bioethics literature on religious views of organ transplantation and donation is relatively scant. It appears that the religions traditionally perceived as "other" (e.g., Catholicism, Judaism, Islam) to tend to receive more attention in the

<u>African American Ethos</u>	<u>European American Ethos</u>
Holistic	Particularistic
Inclusive	Exclusive
Communalistic	Individualistic
Strongly spiritual	Intellectual (secular)
Strongly theistic	Agnostic or atheistic
Improvisational Approach	Structured Approach
Humanistic	Materialistic

These contrastive features were derived from a synthesis of predominant themes in the literature and behavior norms of the groups. It is worthwhile to question Professor Saunders's agenda in making these distinctions since the rhetoric of differences between these two groups maintains a favorable perspective of African Americans and a negative view of European Americans.<sup>77</sup>

Highly salient values among African Americans in the 1970s included, in order of perceived importance by "black Americans": security/survival, power/self-determination, truth-telling, and justice.

### *Jamaicans*

Virtually no literature examines Jamaican or Caribbean views of organ transplantation and donation. Thus, it is helpful to draw upon social science research to gain a sense of Jamaican worldviews that could inform their approaches to these bioethical issues. Significant to this study is the finding by medical anthropologist Elisa Sobo (1993:294) that in Jamaica, "mortality applies to the body and not to the person, who continues to live as a ghost after death." We could extrapolate from this statement that some Jamaicans may be reluctant to donate or undergo transplantation out of concern that transplanted organs may be seen as dead parts of the body. We will see in a later section that this view may cohere with one Jamaican's treatment decision to remain on dialysis.

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<sup>77</sup> I thank Charlotte Ikels for helping me to problematize the rhetoric underlying these distinctions.

The two Jamaicans in this study differed in their treatment decisions. The difference may be attributed to their different ages when immigrating to the US since it is likely that the older a person is at the time of emigration, the greater a person's adherence to their Jamaican worldview. Allison, who was in favor of transplantation, immigrated at age 10, while Barbara, who preferred to remain on dialysis, immigrated at age 18.

### *European Americans*

This is not an ethnic group. But the term is used here to make the distinction between people of an African heritage and European heritage because their cultural traditions differ significantly, and they have played different roles in colonization, slavery, oppression, etc. Europe can be divided into three main culture areas given their highly similar values and beliefs concerning morality, religious traditions, gender relations, public and private domains, etc.: Western Europe, Eastern Europe, and the Mediterranean. It is important to note that even these culture areas represent diverse cultural and ethnic groups. Since the patients with European heritage in this study are second, third, fourth (or more) generation immigrants, the extent to which they adhere to their heritage's cultural meaning systems is unknown.

### *Protestantism*

There is no unifying principle guiding decisions that inform decisions about medical interventions on the body. Many Protestants affirm the value of personal autonomy which warrants medical interventions of the body. According to William May (1985), the donation of body parts to serve others is justified on the altruistic grounds of love of neighbor. However, some Christians are hesitant to donate because of belief in the resurrection (Walters 1988) and thus the concern about the integrity of bodily organs after death.

Baptists do not hold an official position on specific bioethical issues. It is thought that a Baptist's approach to bioethical issues will be "far more tolerant of differing perspectives/solutions than will those of an evangelical/fundamentalist," because of their strongly held beliefs in religious liberty, and the separation of church and state (Simmons 1993:244). Similarly, Presbyterian Churches of the USA are likely to be open to organ transplantation and donation given their theological affirmations of "free and theonomous conscience on all matters of life and death" (Vaux 1991).

The Lutheran tradition secularized their approach to morality and thus rely on reason (rather than religion/faith) when dealing with bioethical issues (Nelson 1993). Lutherans can be characterized as "practical" when working to resolve moral issues, as the following shows:

"The sober recognition that we are less than perfect people living in a far from perfect world, along with the conviction that we are, nevertheless, forgiven sinners are the two benchmarks of a Lutheran moral vision. The former precludes self-righteousness and underlies the sense that often we can do little else but choose between greater and lesser evils" (Nelson 1993:151).

Lutheran bioethics aims to promote works of mercy, love, and justice (Nelson 1993). Accordingly, Lutherans in the US encourage both postmortem organ donation and living donation, recognizing that "the donation of renewable tissue and live organs can be an expression of sacrificial love for a neighbor in need" (Nelson 1991:139).

Methodists are committed to organ donation as an expression of humanitarian ideals (Shelton 1993). According to the Wesleyan Church, a denomination of Methodist, the theological understanding of resurrection does not interfere with organ donation because it refers to a "spiritual body," thus the intactness of the physical body is of no concern (Shelton 1997:206).



literature than the dominant religion in the US (e.g., Protestantism), perhaps in an endeavor by the 'mainstream' to 'explain' the "others'" differences of opinion on various bioethical issues. The scant attention given to Protestantism in bioethics literature may derive from the US folk model of ethnicity, noted in Chapter 1, in which "white, northern European Protestants" are perceived as having no ethnicity (Banton 1983:146 in Banks 1996:68). Further, the scant attention given to Protestants makes sense given their dominance in US society and the fact that people tend to strongly identify themselves as belonging to an ethnic group when they are subject to oppression in the larger society (Banks 1996; De Vos 1995). Consequently, there is little critical analysis of various Protestant denominations' views of bioethical issues. It should be noted that attitudes toward the body form the core of religious groups' approaches toward kidney transplantation and donation. It is also important to recognize that there is a diversity of opinion within each sub-cultural group.

### *African Americans*

According to a group of African American scholars and health care professionals involved in a bioethics workshop, there exists an African American perspective on biomedical ethics (Murray 1992). The African American perspective derives from the unique complex set of experiences shared by many, including: "slavery, segregation, discrimination, poverty and a disadvantaged position with respect to education, health and medical care" (Murray 1992:36). One scholar involved in the workshop, Professor Cheryl Saunders of the Howard University School of Religion, outlined contrasting cultural differences between African and European Americans (Murray 1992:37):

## *Catholicism*

The high percentage of Catholics who were pro-transplant may be related to the Catholic Church's beliefs about the body. The principle of the "totality of the body" governs the Catholic Church's strong position on organ transplantation. According to this principle, "one is allowed to sacrifice a bodily member should this be necessary or useful for the good of his own person as a whole" (Catholic University of America 1967:757).

While the Catholic Church is traditionally reverent of the human body after death because of the body's once and future significance in personhood and resurrection (Ulshafer 1988), the Church favors postmortem organ donation as an act of generosity (Famulari, et al., 1992). Proponents of a more moderate Catholic view contend that the principle of "fraternal charity or love" takes precedence over the principle of totality (Ulshafer 1988). According to this principle, "all members of the human race relate to one another as essentially equal," meaning that one's neighbor may be considered as "another self" (Catholic University of America 1967:146). By this token, organ transplantation from living and cadaver donors is acceptable.

## *Judaism*

The Jewish tradition "calls upon man not to accept the world as a given, to reject the *status quo* and to ever strive for the triumph of life over death, good over evil, and justice over inequity" (Glick 1992:75). This worldview informs many Jewish approaches (e.g., Orthodox, Conservative, Reform) to life and medical ethics.

Jews value the sanctity of life emphasizing its inherent goodness (Cohen 1988). This value is expressed in the concept of *piku'ach nefesh* which means "preserving life" in situations of danger to life (Rosner 1991). Because human life is seen as precious, and as a gift from God, all Biblical and rabbinical laws (except murder, idolatry, and adultery) may be transgressed to

save human life (Cohen 1988). Jewish law even commands that people use all their resources to protect and preserve human life.

Jews generally encourage organ donation and transplantation. The new definition of death (see Chapter 3) has been of some concern to Jews, especially the Orthodox, who have traditionally defined death as the cessation of heart and lung function, but advances in medical technology have allayed concerns that death will not be defined accurately (Cohen 1988). On the one hand, physicians are required to maintain the life of their patient, yet they are not obligated to prolong the process of dying (Weiss 1988). Jewish law also forbids desecrating the human body (e.g., cadaver donation, autopsy), however, this law may be suspended to benefit patients whose lives are in danger (Glick 1992).

Another controversial issue is organ donation from living human donors. The focus here is placed on “risk.” Living donation is accepted as long as the risk posed to the donor’s life or health is substantially smaller compared to the possibility of saving the recipient’s life (Cohen 1988; Weiss 1988).

### *Islam*

Unlike the Jewish tradition that values continuing to work on God’s creation, e.g., the human body, Moslems have traditionally been reticent to change God’s creation because doing so was considered sinful, though today they are more willing to do so for various biomedical interventions (Hathout 1992).

Islamic views of organ transplantation have been examined in different countries. Muslims legitimize modern medical treatments by proving that similar practices appear in the Qur’an, or can be associated with the Prophet Mohammed (Rispler-Chaim 1989; Sachedina 1988). Islamic views about the person’s relationship to their body can be summed up as follows:

“Although life is the gift of God, body is the divine trust given to mankind to enable it to serve God as completely and fully as the wonderful creation of God has made that serving possible” (Sachedina 1988:1085).

A central question is whether an organ may be removed at all. Some scholars believe that people cannot dispose of organs given in trust by God (Rasheed 1992). Many Muslims consider cadaveric organ donation particularly loathsome given religious beliefs about resurrection and Arabic cultural norms about treating the dead with respect (Sachedina 1988). Some scholars find cadaveric donation acceptable because of God’s power to recreate everything, including donated kidneys (Sachadina 1988). Yet other scholars contend that donating kidneys to save another life is a good act and thus justified (Rasheed 1992). Muslim scholars have drawn upon the law allowing autopsy to be performed as a justification for transplantation (Rispler-Chaim 1989).

Another key consideration in Islamic law is bodily purity (Rispler-Chaim 1989). With regard to organ transplantation, Muslims question whether a body part from the dead defiles the body of the living. Different schools have concluded, drawing on legal sources, that an organ removed from the dead body is pure, some would say owing to the ablution after death. There is no unified Muslim policy on organ transplantation, and openness to it is likely to be shaped by cultural context.

#### Religion and treatment decisions

Very few patients (n=6) reported that religious beliefs informed their treatment decisions (two patients were slightly influenced). However, most patients (n=52) considered themselves religious. But since religious perspectives are fundamental to people’s worldviews, they are difficult to explicitly point out as playing a role in one’s thought processes. It is posited here that religious beliefs comprise one’s worldview though to different degrees according to variations in individuals’ upbringing and practices.

There was a significant relationship between patients' treatment decisions and religion (categorized as Protestants, Catholics, and Other) ( $X^2=9.029$ ,  $p=.011$ ). Significantly more con-transplant patients (28/30) (93.3%) were of Protestant denominations than pro-transplant patients (67.3%). Conversely, significantly more pro-transplant patients were Catholic (24.5%) than con-transplant patients ( $n=0$ ). All of the Protestant denominations were evenly divided among pro- and con-transplant patients, though slightly more Baptists were pro- than con-transplant ( $n=23$  vs.  $n=18$ , respectively). Of those patients who were of other religions, four were pro-transplant (2 Jewish, 1 Muslim, and 1 Metaphysics patients), while two were con-transplant (1 Greek Orthodox and 1 Muslim patients). However, the relationship between treatment decision and religion no longer emerged when controlling for ethnicity ( $r=.1223$ ,  $p=.299$ ,  $n=75$ ) suggesting a relationship between ethnicity and religion and/or ethnicity and treatment decision.

Given the contextual descriptions above, it is understandable that both Jews had selected transplantation. The decision to seek a transplant by a Muslim Malaysian patient may be surprising given the cultural resistance to organ transplantation among Muslims in Malaysia. However, perhaps her young age (age 19) and her education level (a fellowship to study economics at the college level), allowed for her greater willingness to undergo transplantation. The Muslim patient who preferred to remain on dialysis drew upon religious notions of the body as the basis for his decision (as will be discussed in greater detail in the following section). It is proposed in this dissertation that lay people may be more likely to forego ethnic and/or religious constraints when they, themselves, are sick and in need of a kidney transplant.

Religious differences were also significantly related to patients' ethnicity (when comparing African Americans to European Americans) ( $X^2=24.181$ ,  $p<.0005$ ,  $n=75$ ). Even when

controlling for treatment decision, this relationship remained strong for the ethnic comparison ( $r=.4372$ ,  $p<.0005$ ). Notably, more African Americans (81.4%) were of Protestant denominations than European Americans (18.6%). More European Americans were Catholic (90.9%) and Other (60.%) than African Americans. Baptist ( $n=41$ , 67.2%) predominated among the ten Protestant denominations represented;<sup>78</sup> the vast majority of Baptists were African Americans ( $n=38$ ). The large number of African American Baptists in this study is consistent with one study showing that half of older African Americans are Baptists (Taylor and Chatters 1991).

In addition, significantly more African Americans (76%) considered themselves religious than European Americans (24%) ( $X^2=5.002$ ,  $p=.035$ , Fisher's Exact Test,  $n=74$ ). Other studies have shown that African Americans tend to be more religious than European Americans and rely on religion/spirituality as a mechanism for coping with stressful life events (Stolley and Koenig 1997; Taylor and Chatters 1991). Because much of people's ethnic identity is based on religious beliefs (Gaines 1978; Domínguez 1989), especially among African Americans<sup>79</sup> (Lincoln and Mamiya 1990:7), it is helpful at times to discuss African Americans' and European Americans' views about treatment for ESRD in terms of their religious identity. The relationships between religion and treatment decision and ethnicity may be due to the trend for treatment decisions to be related to ethnicity, as discussed below.

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<sup>78</sup> The other Protestant denominations include: Episcopalian ( $n=1$ ), Holiness Church ( $n=1$ ), Jehovah's Witness ( $n=1$ ), Lutheran ( $n=3$ ), Methodist ( $n=2$ ), Mormon ( $n=1$ ) (this patient no longer practiced), Pentecostal ( $n=1$ ), Presbyterian ( $n=2$ ), and no denomination ( $n=5$ ). While many of these denominations have many variants (e.g., there are eight identifiable Black Baptist communions in the US [Lincoln and Mamiya 1990:21]), they were not factored into analyses.

<sup>79</sup> Lincoln and Mamiya (1990:7) write: "What is often overlooked is the fact that many aspects of black cultural practices and some major social institutions had religious origins; they were given birth and nurtured in the womb of the Black Church."

### Ethnicity and treatment decisions

The major research question was whether treatment preferences vary between ethnic groups. According to these data, the odds for African Americans being interested in a transplant (1.2:1) were significantly less than the odds for European Americans being interested in a transplant (3.0:1), with an odds ratio of 0.40. There was no significant relationship between ethnicity and treatment choice when performing a Chi-square statistic ( $X^2=2.780$ ,  $p=.129$ , Fisher's Exact Test,  $n=75$ ). The Chi-square relationship was insignificant most likely because of the small sample size. When controlling for age, a significant relationship emerged between treatment choice and ethnicity ( $r=.2355$ ,  $p=.043$ ,  $n=75$ ). Clearly, the relationship between ethnicity and treatment choice is indeterminate; it appears as though other sociodemographic variables effect the relationship.

Other research supports the relationship between treatment choice and ethnicity. According to Clive Callender, a renown Howard University transplant surgeon, among patients eligible for a transplant, 20% of "whites" compared to only 10% of "blacks" receive one. This suggests that various factors are involved in patients' treatment decisions (Dan Gordon 1990).

#### *African Americans*

There are two possible explanations, based on sociological and historical analyses, for the ethnic differences observed in treatment preferences. First, older "blacks" have been shown to experience a significantly greater quality of life on dialysis than older "whites" (Kutner and Brogan 1994). Kutner and Brogan explain their finding in two ways. First, "blacks" have been shown to have better outcomes on dialysis than do "whites," with regard to morbidity and mortality data (see Appendix V) (Eggers 1990; Dan Gordon 1990).<sup>80</sup> Second, they draw upon

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<sup>80</sup> It is unknown whether African American patients are actually aware of this difference in mortality by ethnicity.

reference group theory, which suggests that “a person’s sense of well-being is shaped by the particular context in which it is evaluated” (1994:145). They propose that this theory can be applied to both older “blacks” and “whites.” Kutner and Brogan explain that for older “black” patients in the southern US, dialysis represents an opportunity to receive comprehensive medical care and access to various societal resources<sup>81</sup> that they are otherwise unlikely to have due to disadvantages arising from double jeopardy (Ferraro and Farmer 1995). In contrast, “whites,” Kutner and Brogan explain, experience a worse quality of life on dialysis because they feel “relatively deprived” of their chances to enjoy their later years when comparing themselves to their peers of similar age who are not on dialysis.

Clive Callender similarly explains the lower rate of seeking transplants among African Americans: “It appears as though blacks who get on dialysis are satisfied and afraid to take the option of transplantation” (Dan Gordon 1990:116). Five nephrologists in this study reported that African Americans enjoyed dialysis because of what Kutner and Brogan (1994:147) called “fringe benefits” of dialysis. According to Dr. Young:

“One of the comments that the nursing staff makes is that they love being cared for. No one has ever made a big deal out of them, no one has ever paid much attention to them. I’m not saying all African Americans, I’m just saying there is a population whereby they love the socialization, coming in, and they’re comfortable. They’re very uncomfortable with newer treatments or treatments whereby there aren’t some guarantees. And there are no guarantees with a transplant. So they’re not risk takers. And, not being risk takers, they sort of look at, ‘OK, what does my future hold, let’s think about that, what does my future hold? Am I going to move? ah, I don’t think that IBM’s going to hire me to the Silicon Valley, OK. Is it going to dramatically change my earning potential, ah, I don’t think so. Well, will it restrict me in what I can do? Nah, to tell you I’m kind of comfortable here.’ And they don’t like taking medicines. They got to take all these drugs and the drugs may cause them to look different, you know, and if they tolerate dialysis well, and they get good clearances, then I think that may be an argument for them not to get a transplant. But I don’t think people make decisions because they say, ‘I’ll tell you doc, I’m getting great dialysis here and I know that if I get great dialysis I’ll live 20 years.’ They’re not interested in change.”

Dr. Gilmore similarly commented:

“I hate to generalize or stereotype but I would say that the ones that seek a transplant are probably going to be the ones that are best informed and have, shall we say, the least reason for wanting to stay on dialysis. You have to understand that dialysis itself is a culture, O.K. When people get on dialysis, especially if they are indigent, and they

<sup>81</sup> Resources or “fringe benefits” included in dialysis care are the close monitoring of health status, and intervention on the part of a clinic social worker when a crisis becomes imminent due to an individual’s limited personal income (Kutner and Brogan 1994:146).



don't have a lot of social support out in the community, dialysis becomes a form of social support. They don't want to relinquish that for a transplant. They actually look forward to dialysis treatments because they get tender loving care and they see the same patients over and over again. They form this kind of network that for them is their life. So, the more dependent a patient is on that type of social support, the less interest they're going to have on going out to transplant because it would mean they'd have to relinquish that..."

It is proposed here that a better quality of life, especially among African Americans, leads patients to not change their current treatment status.

Another possible explanation is that many African Americans are distrustful of healthcare professionals and the medical establishment. Given a history of "race"-based discrimination in health care, as described in Chapter 4, some African American patients may be hesitant to place themselves in the potential situation of receiving poor care when undergoing a kidney transplantation.

#### *European Americans*

To fully understand the relationship between treatment status and ethnicity, we must also examine why European Americans tend to seek a transplant instead of remain on dialysis. Two nephrologists (Dr. Olson, Dr. Gilmore) and one transplant surgeon in this study indirectly commented on this pattern. According to transplant surgeon, Dr. Riley:

"There is a large proportion of patients that are probably in a higher socioeconomic status that tend to definitely want to proceed with a more advanced form of treatment for their renal disease, meaning transplantation."

In their experiences with patients, they have found that most patients who seek transplantation tend to be better educated, from a higher socioeconomic background, more self-sufficient, and more involved in their medical care. The underlying assumption is that European Americans tend to have more education and a higher socioeconomic status than minorities. Similarly, in this sample, there was a significant difference by ethnicity (in both ways of categorizing ethnicity) in the average grade of education completed. As Table 7.2 shows, African Americans had completed a significantly lower grade of education compared to others.

**Table 7.2 Two tests comparing ethnicity to education**

Test #	Ethnic Group	N	Mean Grade	Test	Significance
1	African Americans	51	12.5	t=2.714	0.008.
	European Americans	24	14.1		
2	African Americans	51	12.5	Anova	0.025.
	Eastern Europeans	7	15.6		
	Western Europeans	14	13.5		
	Mediterraneans	3	13.3		
	Jamaicans	2	12.5		

When controlling for education, the relationship between treatment choice and ethnicity became insignificant ( $r=.16$ ,  $p=.173$ ,  $n=77$ ). The conflicting results when controlling for age and education in the relationship between treatment decision and ethnicity suggests that all of these variables cannot be individually examined, but are rather interrelated in their impact on treatment decisions. We will see in the sections below how some of these considerations bear out in the reasons patients offered for their treatment decisions.

### **Clinical Demographic Summary**

In addition to sociodemographic variables there were also clinical factors related to patients' treatment decisions. These include the number of years patients have been on dialysis, the timing of patients' ESRD onset, whether patients were informed of the transplant option before or after they began dialysis, and the timing of their treatment decisions. Each of these variables is discussed below.

#### **Years on dialysis**

The number of years on dialysis was significantly related to patients' treatment decisions (Mann-Whitney  $U=399.500$ ,  $p=.001$ ).<sup>82</sup> Con-transplant patients have been on dialysis, on average, longer than pro-transplant patients (4.2 years vs. 2.8 years, respectively). This relationship may be due to the fact that most con-transplant patients are older than pro-transplant

<sup>82</sup> One patient was excluded from analysis because he has been on dialysis 17 years, which is an outlier.

patients and may prefer not to change their treatment status, particularly at an increased age. Yet even after controlling for age, treatment decisions remained correlated with years on dialysis ( $r=.3332$ ,  $p=.003$ ). The difference in time on dialysis may be due to the fact that most patients (with sudden onset of ESRD) start their transplant evaluations shortly after beginning dialysis.

#### ESRD onset: progressive or sudden

It was originally hypothesized that those with a progressive onset of ESRD would have more likely been pro-transplant patients than con-transplant patients since patients with more time to learn about their renal disease and who have become medically stabilized early on in their renal failure would have chosen transplantation. In this study, progressive onset of kidney failure was defined as knowing of the impending kidney failure for at least one month prior to dialysis.<sup>83</sup>

There was no significant relationship between patients' treatment decisions and the timing of their ESRD onset (progressive versus sudden). The majority of all patients ( $n=53$ ) had a progressive onset of kidney failure. Approximately two-thirds of both pro-transplant and con-transplant patients had a progressive onset of kidney failure.

#### Informed of transplant option: before or after initiation of dialysis

A related hypothesis was that patients who have been told about their transplant option before starting dialysis would have more likely been pro-transplant patients, since they would have had more time to consider it. However, no significant relationship emerged. Yet interestingly, of all progressive onset patients ( $n=53$ ), 23 (43.4%) were told about the transplant option after starting dialysis.

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<sup>83</sup> There is no set standard for defining onset status in the nephrology literature. However, since several studies have used one month as the cutoff (e.g., Campbell, et al., 1989; Churchill 1997; Ratcliff 1984), it is used here to facilitate comparison of data.

These data are supported by other research findings. A psychology study of transplant recipients' (n=29) emotional and moral responses to failed transplantation retrospectively examined their decisions to get a transplant using closed-ended questionnaires (Wagener and Taylor 1986). The study found two relevant patterns. The idea of transplantation as a treatment option was presented to patients at the following occasions: to 6% at the time when illness was discovered, to 29% sometime during the progress of the illness, to 34% when dialysis began, to 29% during dialysis, and to 3% after changes in the status of dialysis. These data support the findings of this dissertation research in that a substantial portion of patients were informed of their treatment options after they initiated dialysis. The percentage of emergent cases in Wagener and Taylor's study is unknown but it would explain the large portion of patients being informed following dialysis initiation. The findings from the dissertation study and Wagener and Taylor's study contradict the assertions by the sample nephrologists that they inform progressive patients prior to dialysis initiation. This issue will be examined in greater detail in Chapter 9.

#### Timing of treatment decisions

Patients were asked how long it took them to make a decision about getting a transplant or remaining on dialysis, after the option was proposed. There was no significant difference between patients' treatment decisions and the timing of their treatment decision. The majority of pro-transplant patients (69.4%, n=34) and con-transplant patients (60.0%, n=18) made their decision "immediately" -- in a very short period of time (within hours or a day of being told about their treatment option). The rest of the patients (n=27) (34.2%) had made their decision gradually, over time, over weeks (n=6), months (n=8), years (n=4), or are still waiting to decide

(n=7).<sup>84</sup> These data are likewise found in the study by Wagener and Taylor (1986), in which 34% of patients (n=29) had made their decision to seek a transplant gradually.

Having presented the social and clinical demographic profile of patients in this sample, we are ready to examine the reasons patients expressed for seeking a transplant and remaining on dialysis. The decisions by pro-transplant patients are presented first.

#### PRO-TRANSPLANT PATIENTS: 'I DIDN'T WANT TO BE ON A MACHINE TO BE KEPT ALIVE'

The reasons 49 patients reported to want a transplant pertain to overcoming the physical and lifestyle limits imposed by dialysis. In fact, patients' reasons for seeking a transplant explicitly corresponded to overcoming the adverse circumstances of dialysis. Some of the data presented in this section therefore expand upon data discussed in Chapter 5 regarding patients' experiences of living with renal failure and undergoing dialysis.

There are nine main reasons why patients wanted to get a transplant which include: 1) to get off dialysis; 2) to feel healthier, better; 3) to do things, have more time; 4) to live a more normal life; 5) to eat and drink what I want; 6) to travel; 7) to work; 8) to spend more time with family; and 9) to earn more money and not be on Medicare. Only one patient specified a reason that did not fall within the categories above, namely a combined kidney-pancreas transplant would jointly cure his diabetes and ESRD. Each of these reasons are examined for relationships with patients' sociodemographic characteristics (see Table 7.3). Over half (n=29) of the patients

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<sup>84</sup> Of these patients, five were still unsure, one was waiting for medical problems to clear, and one was waiting for the transplant evaluations to finish. There were two patients who had changed their mind during the evaluation process and the timing of their decisions was unknown.

indicated more than one of these reasons for wanting a transplant. All of these reasons are intrinsically related, as shown in the statements presented below.

**Table 7.3 Sociodemographics of patients by reason selected to get a transplant, N (%)**

	Reason 1 32 (65.3)	Reason 2 15 (30.6)	Reason 3 11 (22.4)	Reason 4 13 (26.5)	Reason 5 8 (16.3)	Reason 6 10 (20.4)	Reason 7 7 (14.3)	Reason 8 8 (16.3)	Reason 9 2 (4.1)
<b>Gender</b>									
Female	13	9	7	5	4	3	3	4	0
Male	19	6	4	7	4	7	4	4	2
Mean Age	43.7	44.3	45.6	52, p=.034	51.4	52.4, p=.047	34.4, p=.036	41.5	50.5
<b>Ethnicity</b>									
African American	20	8	6	6	4	2	3	5	2
Western European	6	1	1	1	1	4	1	1	0
Eastern European	4	2	1	4	1	2	2	1	0
Mediterranean	1	2	1	1	1	2	0	0	0
Asian	0	0	1	0	1	0	0	0	0
Jamaican	1	1	1	1	0	0	1	0	0
Lebanese	0	1	0	0	0	0	0	1	0
<b>Religion</b>				p=.023					
Catholic	7	5	2	4	2	5	3	3	0
Protestant no denomination	3	1	2	2	1	1	0	2	0
Baptist	17	8	4	3	3	2	4	3	2
Holiness church	0	1	0	0	0	0	0	0	0
Lutheran	1	0	0	0	0	0	0	0	0
Methodist	1	0	0	0	0	0	0	0	0
Presbyterian	1	0	1	0	0	1	0	0	0
Metaphysics	1	0	1	1	0	0	0	0	0
Jewish	1	0	0	2	1	1	0	0	0
Muslim	0	0	1	0	1	0	0	0	0
<b>Marital Status</b>									
Single	16	6	3	3	2	3	2	1	0
Married	11	6	4	6	5	7	4	4	2
Divorced/Sep	4	2	3	2	1	0	1	3	0
Widowed	1	1	1	1	0	0	0	0	0
Mean Education	13.4	13.2	14.1	14.6, p=.056	13.9	13.5	12.4	13.2	10.5
<b>Work Status</b>									
Employed	13	8	7	6	4	6	2	4	0
Unemployed	19	7	4	6	4	4	5	4	2
Mean Income, \$	17,728	19,719	17,141	21,747	11,782	28,753	8,332	12,132	N/A

Reason 1: To get off dialysis  
Reason 2: To feel better, more healthy  
Reason 3: To do things, have more time  
Reason 4: To live a more normal life  
Reason 5: To eat/drink what I want  
Reason 6: To travel  
Reason 7: To work  
Reason 8: To be with family more

Reason 9: To not be on Medicare

### **To Get Off Dialysis/Not Be Tied Down**

By far, the most common reason patients desired a transplant was to end reliance on dialysis. For these patients, dialysis is disliked because of its concomitant pain from the needles, time invested in being at the dialysis center throughout the week, and the sense of being forever “tied down” to a machine which interferes with patients’ “freedom” and “independence.” Statements reflecting these concerns are as follows:

Ginnie: “To allow me to be more independent, allow me to feel better, stop me from coming to dialysis.”

Jerome: “Because it seemed to be a better option as opposed to staying on dialysis forever... I didn’t want to be on a machine to be kept alive.”

Douglas: “[I’ll] do anything to stop getting stuck all the time, [it still hurts].”

The themes of “freedom” and being “tied-down” will become even more apparent in the discussion of other reasons patients indicated for wanting a transplant.

### **To Get Healthier, Feel Better**

The second most commonly selected reason was that patients believed that transplantation is a healthier form of renal replacement therapy than dialysis. Patients said they wanted a transplant because it would make them healthier, as the following statements illustrate:

Bruce: “I want to be healthy again.”

Hazel: “If it can help me, I want one, you know... If it’s going to help my health.”

For some, (e.g., Annette) a transplant would help them to live a longer life. Other patients, hoping that a transplant would eliminate the adverse effects of dialysis, stated:

Jan: “I’m tired of feeling the way I am. I am tired of dialysis, period. A transplant will help me a lot.”

Rosa: “I knew it [transplant] would be a better way of living. Those needles are terrible, it had to be better.”

Louise: “Getting a transplant is the best thing to do. [I want] to be healthy, feel better, be able to urinate, get back to normal, the way I was born. To be able to pee is normal, healthy. Everything I drink stays in me. It’s terrible

[because I get “full,” feel “miserable,” “short of breath,” and “sick” waiting until dialysis for all the fluids to be removed].”

Some others noted that by getting a transplant, they would no longer feel worn out or get infections as frequently. Interestingly, patients did not express concern about side-effects of the immunosuppressant drugs despite most of the patients having learned about them in consultations with the transplant team during their evaluation process, prior to placement on the waiting list. Patients’ lack of concern about side-effects may be due to the fact that none had experienced a previous transplant, as a criterion of eligibility in this study.

### **To Do Things, Have More Time, Freedom**

Because patients must commit many hours of their week to dialysis, some disparage the fact that they have little time to do the things they prefer to do. Patients expressed this attitude when they stated their reasons for wanting a transplant:

Chantal: “[I want] to be able to eat, get up and go where I want without arranging dialysis, to be free without having to be tied to a machine.”

Other patients disliked the complexity of having to plan their daily schedules around dialysis and work or school:

Monique: “I don’t want to have to come to dialysis three times a week [because it] takes a strain [in my life]. [EG: how it was a strain?] I always have to make room in my schedule [for it].”

Tammy: “[I want] to be over with all this other stuff... to live more normal life without so much time taken out... I don’t want to plan only for Tuesdays and Thursdays, I want to be able to plan for Monday, Wednesday, and Friday.”

### **To Live a More Normal Life**

When patients spoke about wanting to live a more normal life, they referred to all of the reasons why people would want a transplant. But some also recognized that life with a transplant would be more, but not entirely, normal than life on dialysis. For instance, patients expressed a desire for a transplant:



Chantal: "To live a normal life again. I know it won't be normal-- it's a tradeoff, the possibility of having to come back [to dialysis], the kidney won't take, rejection, taking medications..."

Simon: "I just want to live that's all, almost function normally."

There were four significant relationships between patients who indicated this reason and their sociodemographics. First, those who indicated this reason were older than those who did not (age 52 vs. 42.2) ( $t=2.190$ ,  $p=.034$ ). Second, those who indicated this reason had completed more years of education than those who did not (14.6 vs. 12.9 years) ( $t=2.394$ ,  $p=.056$ ). Third, proportionally more patients who specified this reason were of Catholic and other religious backgrounds compared to those who did not ( $X^2=7.582$ ,  $p=.023$ ). Fourth, most of these patients were of a higher SES (level 2) compared to those who did not indicate this reason ( $X^2=9.954$ ,  $p=.019$ ). These relationships may be related to the possibility that those who selected this reason had already established their careers (as indicative of having a higher education and SES level), and dialysis was seen as an interruption of them. Further investigation into these trends would be worthwhile.

### **To Eat and Drink What I Want**

As discussed in Chapter 3, ESRD patients must adhere to a very limited diet. Patients expressed frustration with their current diet (e.g., noting cravings for oranges and frustration with constantly being thirsty). Understandably, patients explicitly stated that they desired a transplant in order to eat and drink whatever they wished, without limits on the amount of food they can eat. As Jerome stated, "[I will be] allowed to eat and drink more and more."

### **To Travel**

The desire to travel was one reason patients wanted to get a transplant. Although there are some possibilities for traveling, often there are many limitations involved. Patients who travel may be able to dialyze at facilities in other cities. Although social workers usually help

coordinate their patients' dates and times of dialysis in other cities, organizing dialysis at other centers is not always easy. The factors preventing patients from dialyzing elsewhere are the lack of openings at a given center, or their insurance fails to cover dialysis out of state. There are even dialysis cruises available for patients where dialysis staff are on board to monitor patients while dialyzing, but most insurance companies and Medicare do not cover dialysis in this situation. In his explanation for wanting a transplant, Simon conveyed the difficulty with traveling: "I don't want to be on dialysis... You can't really go somewhere out of town. I have to try and find a center. It can be hectic after a while..."

Others, like Maureen, find it hard to travel because of the difficulty in finding proper food on the road or because the closest dialysis unit is far from the vacation spot. While patients desire to travel to other cities, they may fear to do so because of their concern with dialyzing at a 'foreign' center, as five patients reported. They feared the lack of cleanliness and poor quality of other facilities and how other technicians will treat them. One patient, Mindy, noted her discomfort with dialyzing elsewhere because she "got used to each tech's ways."<sup>85</sup>

There were two significant relationships between those who indicated this reason and their sociodemographics. First, those who specified this reason were older than those who did not (age 52.4 vs. 42.6) ( $t=2.040$ ,  $p=.047$ ). Second, those who indicated this reason were more likely to be European American ( $n=8$ ) than African American ( $n=2$ ) compared to those who did

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<sup>85</sup> Interestingly, while many patients desire the freedom to travel without the constraints imposed by hemodialysis, few ( $n=7$ ) had ever been on peritoneal dialysis, which allows for more freedom of movement. These seven patients switched to HD because they had many peritoneal infections. When patients were asked whether they had ever considered PD as a treatment modality, most were disinterested in it because of the following reasons (some reasons were provided by the same patient): the high likelihood of infections ( $n=9$ ), the need for cleanliness in one's house ( $n=7$ ), the need to do treatments everyday and throughout the day ( $n=6$ ), the fear of being responsible for the treatment process when something may go wrong ( $n=7$ ), the fact that they interact with children often who may spread germs ( $n=3$ ), the lack of support from one's spouse ( $n=2$ ), the idea of a tube hanging out of one's stomach ( $n=2$ ), not knowing enough about it ( $n=2$ ), and wanting to try transplantation first ( $n=1$ ). Seven patients offered no reason. Four patients were told by their doctor not to do PD for health reasons. Six patients were never told about PD as a treatment option. Ten patients did not mention PD during the interview.

not specify this reason ( $X^2=8.961$ ,  $p=.008$ ,  $n=46$ ). Perhaps these patients, given their age, had greater experiences traveling prior to ESRD and longed to continue traveling.

### **To Work & To Be Off of Disability**

Patients asserted that a transplant would enable them to find a job, which is difficult to do with poor health and a limited time schedule. A transplant would free up time in Allison's schedule to allow her to concentrate on her schooling to become a nurse. Being able to work and have an increased income meant that Joshua "could buy and [do] things I want to do, like go out to dinners, go to the movies, take the kids out." Two patients noted their desire to get a transplant in order to be off of Medicare.

One such patient (Joshua) indicated his dislike of being paid once a month when he used to be paid every week. Even a patient (Roland) who changed his mind during the study period to seek a transplant voiced similar financial concerns with being on dialysis that formed part of his incentive to seek a transplant: "I'm not used to living on a fixed income. I worked the majority of my life." He elaborated how he could not afford a car, and hated public transportation because, he noted, there are always crazy people on the bus.

Those who specified this reason were more likely to be younger than those who did not (age 34.4 vs. 46.3) ( $t=-2.162$ ,  $p=.036$ ). It makes sense that older patients, especially those who have retired, would not be motivated by this reason.

### **To Spend More Time with Family**

Patients specified that they wanted a transplant in order to spend more time with their family, notably, their children or grandchildren. For instance, patients commented:

Monique: "I have a five year old son to raise and could be spending time with him" instead of on dialysis.

Wilma: "I'd love to live a normal life as best I could, take care of my grandbabies the best I could, go on with things I used to do."

Two male patients (Emmanuel, Roy) expressed their desire to do activities with their children if they had a transplant. Another male patient, Albert, believed that a transplant would enable him to live longer and said, “I would like to see myself retired at 63. I would like to see my daughter graduate and go to college.”

Most of the patients who indicated this reason tended to be of a lower SES (levels 4 and 5) than those who did not ( $X^2=8.982$ ,  $p=.030$ ). It is unknown why this relationship emerged. Further investigation into this trend would be worthwhile.

### **Goal Theory**

In writing about research on decision making, Mathews (1987:55) emphasizes the importance of investigating how decision-makers themselves frame the decision problem, that is, how they define the goal or set of goals to be pursued. Thus, to better understand possible factors motivating patients to seek a kidney transplant, pro-transplant patients were asked if they had any goals they hoped to achieve by getting a transplant.<sup>86</sup> Of 49 pro-transplant patients, 32 (65.3%) had a specific goal in mind, 15 (30.6%) had none, 1 (2.0%) had never thought about it, and 1 (2.0%) was missing. Those with goals were evenly divided by gender. Patients’ goals reflected the same reasons why they wanted to get a transplant.

Goals patients specified for seeking a transplant can be characterized by two qualities: generality and immediacy. First, a general goal was to end dialysis to allow for more time in other activities of life. More specific goals were to work and to travel. With regard to health, patients generally wished to feel better overall. A few specified that they wanted to no longer feel tired or pain. Second, patients’ goals were characteristically achievable immediately and

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<sup>86</sup> Analysis of responses by only pro-transplant patients is conducted here since the question of goals for con-transplant patients made little sense.

relatively soon after getting a transplant. As soon as patients recovered from the surgery, they could achieve their goal of resuming their pre-ESRD daily activities, and ideally be in better health. Their goals were not long-term goals to be achieved over time.

It was hypothesized that patients might have specific life goals that were achievable only through obtaining a transplant (e.g., play music in a band). Most of the goals patients expressed, however, were reactions to their current situation. In other words, patients sought a transplant in order to change their current life situation imposed by the dialysis routine.

One nephrologist, Dr. Gilmore, confirmed this observation: "In my patient population, career goals are usually not the overriding issue because most of my patients are indigent and their careers are basically not particularly striving, if you know what I'm getting at." It was therefore surprising to find that only one patient, Chantal, had a specific goal of long-term self-development. Chantal explained that "In 1995 I was ordained as a minister in church. It was prophesied that I would go to Africa and the only way I can is if I can get off dialysis."

The expectation of patients having goals that reflect future orientation and self-enhancement stems from the literature on goal-theory in decision making. The very concept of having a goal may reflect a Western concept of self that relishes self-development through the achievement of goals. Further, patients' treatment decisions appear to be based not on what the "rational man" would do (Young 1982), but on emotional, experiential, and social considerations, like being sick of living with restrictions associated with dialysis. Goal theory may not be entirely applicable to patients with a chronic illness.

For many patients, their chronic illness becomes an all-consuming and central feature of their self identity (Barnard 1990; Charmaz 1995; Alexander 1982). This means that the goals patients design for themselves are inextricably bound to the elimination of the all-consuming

nature of their chronic illness. For dialysis patients, it makes sense that their goals in getting a transplant are framed in terms of the immediate forms of self-enhancement incumbent on the successful operation. Some patients could achieve the non-health related goals at present but only on a limited basis. That is, some people were already employed or in school, or had been spending time, albeit limited, with their children. Having reviewed patients' reasons for wanting a transplant, we are ready to examine the reasons why patients desired to remain on dialysis, discussed below.

#### CON-TRANSPLANT PATIENTS: 'IF IT'S NOT BROKE, DON'T FIX IT'

In this section we consider the choices made by thirty patients in this sample to remain on dialysis. The discussion and statistical analyses are based on the reasons provided at the time of the initial interview (based on the first card sort task as described in Chapter 2), however, results from the second card sort will only be presented when relevant. Below we examine each reason patients indicated for not wanting a transplant and provide patients' comments to demonstrate the complexity of the meanings.<sup>87</sup> Two of the reasons patients indicated (knowing transplant recipients and costs) will be discussed in later sections because of their broader import. Table 7.4 summarizes the responses to the card sorts in the first and second interviews. Table 7.4 also depicts the extent of changes in patients' reasons over a three month period of time. The majority (n=29) of the patients indicated more than one of these reasons for remaining on dialysis in both the first and second interviews. See Table 7.5 for a summary of the demographic breakdown of patients selecting each reason. Each of the reasons patients' indicated are

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<sup>87</sup> This section is organized and analyzed statistically according to the reasons indicated from the first card sort task. It is important to note that some comments patients provided about each reason/card they selected could have been categorized under different reasons/cards.

examined for relationships with patients' sociodemographic characteristics. Data from patient and healthcare professional interviews and social science literature are presented to supplement this discussion.

**Table 7.4 Number, percent, and change of reasons for remaining on dialysis between the first and second interviews (n=30)<sup>1</sup>**

Reasons	Interview 1		Interview 2		No. (%) Change <sup>4</sup>
	No. (%)	No. (%) Ranked #1 <sup>2</sup>	No. (%)	No. (%) Ranked #1 <sup>2</sup>	
Doing OK on dialysis	25 (83.3%)	9/20 (45%)	23 (76.7%)	13/21 (61.9%)	2 (6.7%)
Do not want to be 'cut on' <sup>3</sup>	22 (73.3%)	8/16 (50%)	17 (56.7%)	5/14 (35.7%)	5 (16.7%)
Know unsuccessful kidney recipients	16 (53.3%)	1/11 (9.1%)	13 (43.3%)	0/12	3 (10%)
Fear being worse-off	15 (50.0%)	0/10	10 (33.3%)	1/8 (12.5%)	5 (16.7%)
Fear transplant medications	14 (46.7%)	0/8	13 (43.3%)	0/10	1 (3.3%)
Fear foreign part in my body	11 (36.7%)	1/7 (14.3%)	6 (20%)	0/3	5 (16.7%)
Do not want to have tests	9 (30.0%)	0/4	5 (16.7%)	1/4 (25%)	4 (13.3%)
Fear of death	7 (23.3%)	1/5 (20%)	5 (16.7%)	3/5 (60%)	2 (6.7%)
Too old	7 (23.3%)	2/2 (100%)	7 (23.3%)	0/5	0
Do not want to go through disappointment of rejection	5 (16.7%)	0/2	14 (46.7%)	0/13	9 (30%)
Concerned about the costs	5 (16.7%)	1/3 (33.3%)	6 (20%)	1/5 (20%)	1 (3.3%)
Have kids to take care of	2 (6.7%)	0/0	2 (6.7%)	1/2 (50%)	0
Do not want a kidney from a different "race"	2 (6.7%)	0/1	2 (6.7%)	0/1	0
Religious reasons	2 (6.7%)	0/0	3 (10%)	0/1	1 (3.3%)

1. The reason 'I do not want to return to work' is not included in the chart because no one ever chose it, but laughed upon seeing that card.

2. These calculations are based on reasons that were ranked as the most important reason. The denominator represents the number of reasons that were ranked. Reasons were not ranked if they were provided outside of the card sort process.

3. The term "cut on" was an emic term used by primarily African American patients. It denotes surgery.

4. The percent of change may actually be lower than is presented because some patients did not do the card sort again. Four patients refused to do the card sort a second time because they said their reasons for not wanting a transplant have not changed. Two patients refused to do the card sort a second time, but their first responses are still in place. One patient was too ill to redo the card sort and her responses are still in place.

**Table 7.5 Sociodemographics of patients by reason selected to remain on dialysis, N (%)**

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Total	25 (83.3)	22 (73.3)	16 (53.3)	15 (50)	14 (46.7)	11 (36.7)	9 (30)	7 (23.3)	7 (23.3)	5 (16.7)	5 (16.7)	2 (6.7)	2 (6.7)	2 (6.7)
Gender			p=.072	p=.060				p=.009						
Female	14	13	7	6	8	6	6	1	4	4	3	1	1	1
Male	11	9	9	9	6	5	3	6	3	1	2	1	1	1
Mean Age	51.8	53.6	52.2	55.9	55.9	48.3	56.4	54.1	61.9	52.4	54.2	55.5	58	47.5
Age	p=.051					p=.029			p=.007					
Ethnicity*			p=.064			p=.068								
African American	19	17	15	13	9	10	8	7	7	3	3	2	2	2
Western European	5	4	1	1	3	0	0	0	0	1	2	0	0	0
Mediterranean	0	1	0	1	0	0	0	0	0	1	0	0	0	0
Jamaican	1	0	0	0	1	1	1	0	0	0	0	0	0	0
Religion														
Pentecostal	0	1	0	0	1	0	0	0	0	0	0	0	0	0
Greek Orthodox	0	1	0	1	1	0	0	0	0	1	0	0	0	0
Protestant no denomination	3	2	2	1	1	2	1	0	0	1	0	0	0	0
Baptist	16	13	13	11	8	7	8	7	7	2	3	2	2	1
Episcopalian	1	1	0	0	1	0	0	0	0	0	1	0	0	0
Lutheran	1	1	0	0	0	0	0	0	0	0	1	0	0	0
Methodist	1	0	0	0	1	0	0	0	0	1	0	0	0	0
Presbyterian	1	1	0	0	0	0	0	0	0	0	0	0	0	0
Mormon	1	1	1	1	1	0	0	0	0	0	0	0	0	0
Jehovah's Witness	0	0	0	0	0	1	0	0	0	0	0	0	0	1
Muslim	1	1	0	1	0	1	0	0	0	0	0	0	0	0
Marital Status				p=.055					p=.040					
Single	4	3	2	0	1	2	0	1	0	1	1	0	0	0
Married	6	4	4	4	4	1	2	3	1	2	2	0	0	0
Divorced/Sep.	11	10	8	6	6	6	5	2	2	1	2	1	2	2
Widowed	4	5	2	5	3	2	2	1	4	1	0	1	0	0
Mean Education	12.7	12.7	12.5	12.5	12.9	11.8	11.2	11.6	11	13.4	12.6	12.5	10.5	12.5
Education							p=.066		p=.072					
Work Status														
Employed	7	5	5	5	4	3	1	2	1	2	1	1	0	0
Unemployed	18	17	11	10	10	8	8	5	6	3	4	1	2	2
Mean Income, \$	10,864	12,331	12,456	16,042	12,526	11,377	10,729	16,864	10,681	14,448	8,895	12,066	4,200	10,764
				p=.038										

\* Statistical analyses compared only African Americans to European Americans

Reason 1: I am doing OK on dialysis

Reason 2: I do not want to be cut on / have surgery

Reason 3: I know unsuccessful transplant recipients

Reason 4: I fear being worse off with a transplant

Reason 5: I fear transplant medications and their side effects

Reason 6: I fear a foreign part in my body



Reason 7:	I do not want to take the tests to get listed for a transplant
Reason 8:	I am afraid of death
Reason 9:	I think I'm too old for a transplant
Reason 10:	I do not want the disappointment of a transplant not working
Reason 11:	I am concerned about the costs
Reason 12:	I have kids to take care of
Reason 13:	I do not want a transplant from a different race
Reason 14:	I have religious reasons.

### **Doing OK on Dialysis**

The majority of patients (83.3%) did not want a transplant because they felt that they were doing well on dialysis. Those who indicated this reason were significantly younger than those who did not indicate this reason ( $t=-2.042$ ,  $p=.051$ , age 51.8 vs. 61.2). 83.3% of European Americans and 82.6% African Americans, and one Jamaican provided this as a reason to remain on dialysis. Overall, patients expressed that they felt in good health, adjusted to, and comfortable with dialysis. They also mentioned that they even maintained residual kidney function (as evidenced by the limited ability to make urine). According to one social worker, Monica, some patients remain on dialysis because their health takes on a new baseline and they forget how good they could feel.

Patients conveyed, in different ways, that they were doing fine on dialysis and thus a transplant was unnecessary. Pauline stated this idea succinctly: “since hemo is working for me, don’t knock it.” She further explained: “if it’s not broke, don’t fix it.” If her dialysis was not going as well as it was, she noted, she might consider a transplant. Another patient, Clifford, said how he has become adjusted to dialysis, for now “I can go longer during the day, and am getting used to taking medicines... I resolved that it’s something I have to do.” Another patient explained that a transplant was unnecessary since she could still urinate and functioned well on dialysis:

Shirley: “I’m not yet ready for it. I still have some [urinary] function... I don’t think I have to have one now. I’m feeling all right. When the time comes... I’ll wait till I need it. I won’t do anything unless I need it. Why should I

push the issue unless I need it? ... I don't know. I must not be ready because [I seem OK, feel good]... why mess up a good thing?"

As these comments suggest, patients might consider a transplant if they were not doing as well as they currently were physically. In fact, 11 (36.7%) patients indicated that they would consider getting a transplant if their health worsened. Similarly, a study of treatment decision making by elderly Medicare patients found that patients' assessment that their illness episode was not serious was the most often cited reason for not seeking medical care (Hurwicz 1995:229).

### **Do Not Want to Be Cut On**

A majority of patients (73.3%) chose not to get a transplant because they did not want to undergo surgery. There were no significant relationships between the sociodemographic variables and indicating this reason. African American patients primarily spoke of transplant surgery in terms of the idiom of "getting cut on" or "being cut on" though its meaning varied slightly among patients. Its meanings included: a) not being prepared to undergo transplant surgery because of the need to recover from prior surgeries, b) the notion that one surgery requires further surgery, c) its concomitant pain, d) the patients' lack of control, and e) the possibility of death. Below, examples of each theme are presented.

### **The need to rest and recover from prior surgeries**

Eight patients (36.4%) explained their dislike of surgery in terms of needing time to rest and recover from prior surgeries. All but one of these patients were female and they were evenly divided by ethnicity. Many patients have had serious clinical events such as heart attacks, strokes, and amputations that have landed them in the hospital for periods of time. By the time patients began dialysis, they have had at least one or two surgeries for the placement of the graft

or fistula (temporary and/or long-term) not to mention having to endure the tri-weekly needle sticks preparing them for dialysis, and occasionally additional surgeries to repair clotted accesses. Consequently, many patients desire a respite from the hospital environment, an unlikely scenario should they chose a transplant. Statements exemplifying this attitude are the following:

Donna: "Ever since I've been sick I had so many surgeries and been cut on... I've had five grafts, gall bladder removed, thyroid removed, hemorrhoidectomy. I'm tired of them. If it didn't work and I'd come back to dialysis I would be horrified. That would be terrible. I'm mobile, able to do things." [She mentioned how doctors tell patients how a transplant will happen but she interjected that it does not happen that way and that patients actually return to dialysis... She did not like this possibility.] "Why go and take that chance? They don't remove the kidney and they leave it in you. [I do not want to be cut on because] I'm tired of it, scars, cosmetic reasons."

Juliet: "[I am] undecided if I want to go through all that [the transplant involves]-- the surgery-- I've had so many. I'm not looking forward to another one."

Roland chose not to get wait listed for a transplant because he was: "not mentally and physically ready [since] I had three operations and my body was sore and not ready to be cut on again... [The] operations were so close together, right after another... I had an infection from my subclavian catheter that lasted one month... I was in a lot of pain, longer than they said. I don't feel like I healed properly.... I wanted to believe what [the doctor] was saying but was not ready to go back under the knife. I don't like people calling the shots about my body and life... I don't want to be cut on. This is a biggie! That's what took me so long to get a fistula."

### Surgery leads to more surgery

An unexpectedly common notion of surgery is that one operation leads to another or further medical care. Five patients (22.7%) expressed this view, all of whom were African American. Some of these concerns are associated with fears of kidney rejection. The following statements exemplify this view:

Michael: "I don't like the idea of being cut open. I avoided it all these years... Once they start they never stop. Everyone you talk to around here, that's what they say - they're in the hospital forever. It's always going back to another operation."

Virginia: "Once they start to cut, they always find some other reason to cut you and I don't want to go there. If I stay on dialysis I know they will cut on me for another graft, but I can deal with that... [It's] just the idea [of getting cut]."

Clifford: "I heard about six out of ten people either had to have two to three retransplants or it didn't work like five years down the road. That people get a transplant and have to have more surgeries for it..." (In a later interview he stated): "What I heard, the rate of success is not worth all the trouble of getting one. You always have to go back to get another one."

### *Etic perspective*

How these patients came to hold the belief that surgery begets more surgery is unknown. One hypothesis is that these patients based their views on their own experiences. If these patients tended to access health care later than earlier for a given problem, it is likely that they would have required a greater amount of treatment to remedy problems that had been neglected over time. Generally, when patients seek help for a medical problem early in its prognosis/development, it is easier to remedy it with fewer drastic measures. This hypothesis was tested using the variable 'onset of kidney failure' as a proxy for the timing of health seeking practices among this subgroup of patients. It was expected that those with sudden onset of kidney failure would be likely to share the views expressed above. The data show that of these five patients, only one had a sudden onset of kidney failure. Since this hypothesis fails to explain these data, this anomaly requires further investigation.

### *Emic perspective*

From their statements, it appears that patients based their understanding on their observations of transplant recipients. Two patients (Michael, Virginia) indicated that they got this idea "from around here," meaning, having seen other patients go through the process of multiple surgeries. The social environment of dialysis treatment therefore plays an important role in patients' treatment decisions, as will be shown later in this chapter. In addition, patients also used statistical data (e.g., "the rate of success") regarding the clinical outcome of transplantation to form their understanding of surgery. This is important since it reflects, in part, patients' reliance on biomedical data to shape their decisions. Yet information learned from clinicians is, in this and other cases, modified by another source of empirical data -- patients'

own experiences and observations. We will see later on that patients frequently draw upon and modify their sense of clinical data to formulate their treatment decisions.

We can deconstruct the idea that surgery leads to further surgery by reference to an African American folk notion of the body. According to Snow (1991), lower-class African Americans (primarily from the South) maintain the view that illnesses are caused by natural and supernatural processes. The body is susceptible to natural illnesses through exposure via the body's natural openings to environmental forces, e.g., air, food, germs. Such illness-causing agents do not cause illness immediately, rather they lodge in the body until a person becomes weak from not taking proper care of oneself. The body is viewed as a container with connecting passages in which substances move from top to bottom and visa-versa. All parts of the body are connected through the bloodstream.

These views of the body were also expressed by African American women in Cleveland in their notions of breast cancer etiology (Marks 1998). Biomedical interventions were seen by African American women of varying ages and education levels as "dangerous" because they "interfered with natural processes" by the use of synthetic equipment or substances. According to Marks, her informants expressed the view that "anything that interferes with the natural operation of the body or exposed the body to unnatural forces could cause trouble" (1998:320).

Drawing upon this folk conception of the body, the views of the African American patients in this study make sense. Specifically, if surgery allows for exposure to environmental forces, e.g., air, then patients may become sick at a later time. Surgery, as an "unnatural process," may be inherently harmful. In addition, if a part of the body is acted upon, e.g., the lower back during a transplant surgery, then other parts of the body may likely be effected later on.

### The lack of control/trust/fear of accidents

Major surgery such as kidney transplantation requires being under anesthesia for several hours. Three African American male patients (13.6%) considered their lack of control a particularly difficult aspect of that situation. For instance, Andrew's view was shaped by a problem with a recent surgery to insert a graft into his arm. He had three surgeries because an artery was mistakenly cut, and consequently he notes, "they had me all discombobulated." To Andrew, being 'cut on' meant:

"Not being in control of the situation. Being in someone else's hands. Have to trust the surgeon, anesthesiologist... Before I do it again [surgery], I'll have to trust them. It's a serious type of operation..."

Another male patient explained that he did not like surgery because:

Clifford: "I have no control over it. I'm laying there and anybody [could hurt me but I have] no control. [The problem is that doctors] can make a mistake, mess up and there's nothing I can do to protect myself... I like to have some input to what happens to me... Nobody knows me the way I do. Anything can happen."

This patient's concern with getting "cut on" was not a matter of trusting the doctors *per se*, (since he said he has been seeing doctors all his life) nor was it a matter of being in pain (since he's always had enough pain relief). Rather, his main concern related to the effect of operations on his body physically:

Clifford: "From my experience, every time you get [an operation, you] get weaker... [Operations] make you physically weaker. So I want less operations as I can have... Every time you have an operation, it takes something out of you."

Another patient, Roger, did not like surgery because he did not have full trust in doctors since accidents happen. He mentioned the case of a mistaken arm amputation in the news. Given his fear of accidents, this patient noted why he was resistant to getting a transplant:

Roger: "I might have to get cut on so many times if it ain't no good, I have to get cut open and take it out and put in another one."

While much literature notes that African Americans distrust physicians due to medicine's history of "race"-based practices, patients in this study reported that racial concerns did not figure into their fear of the lack of control during the process of surgery.

Taking a chance on rejecting and dying: "There's no guarantee"

Patients indicated that surgery was a concern because of the possibility of rejection and dying from the transplant operation itself. Six patients (four males, two females) expressed these concerns through the idioms of "guarantee" and "chance." For instance, patients made the following comments:

Andrew: "[There's] no guarantee it would last... If it's guaranteed it would work and I could go back to work, I'd get a kidney transplant, but there's no guarantee."

Georgia: "I would want to get off dialysis but I'm scared of the operation. There's no guarantee that the kidney will work. I don't want to go through all that because some people, their body rejects [it]."

Elliot: "The way I see it, it's not guaranteed, so many things can happen. Put it in, it might not work, you still got to do dialysis. It might be a weak kidney, you still have the same problems [of having to do dialysis]... it's a big risk...50-50% chance... They don't guarantee that you'll be new again. They don't know. You have a good chance, but no guarantee that if they put a kidney in you..."

The fact that all of the patients who expressed concern over lack of guarantee of transplantation's success were African American may be related to African Americans' history of poor health and poor experiences within and seeking access to the healthcare system. Recall in Chapter 4 that African Americans have historically received (and arguably continue to do so)<sup>88</sup> less adequate healthcare than the undefined group of "Caucasians." It is also possible that these patients are aware that African Americans generally have a shorter life expectancy than undefined "Caucasians"<sup>89</sup> (National Center for Health Statistics 1997) and thus do not find it

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<sup>88</sup> See, for instance, Peterson, et al., (1994); Williams, et al., (1995); Todd, et al., (1993); Adler, et al., (1993). Ethnicity is compounded by socioeconomic status, particularly in the case of African Americans who tend to be in low socioeconomic strata (Feinstein 1993; House, et al., 1990).

<sup>89</sup> One of the problems with using the category "Caucasian" is that it does not account for the varieties of health experiences among the diverse groups of people that comprise this US "racial" category, e.g., the poor vs. wealthy, rural vs. urban dwellers, various religious groups, etc.

worthwhile going through the rigors of transplantation. It is perhaps with this cautionary stance that African American and other minority dialysis patients exhibit resistance to undergoing the transplant surgery, fearing that they would be highly likely to experience clinical problems.

### The pain of surgery

For two African American patients (Pauline, Gloria), being “cut on” meant surgery and its “after effects” (side-effects), most notably, pain. To explain why she did not want to be cut on, one patient, Gloria, narrated how her graft in her arm clotted and how she required surgery to clear it. Gloria recounted how the doctor did not sew up the wound after surgery but left it open for her to clean. However, she would vomit whenever she tried to clean it. But for her, the problem was inadequate pain relief following surgery. She compared the pain to being “worse than having a baby” and “like a lighter flame on my skin.” Gloria concluded, “When the pain relief wears off it hurts. That’s why people don’t like to be cut on.”

The diversity of examples above of the term being ‘cut on’ attests to its polysemous quality within informants’ illness experiences. To recapitulate, the distinct configuration of meanings associated with being ‘cut on’ includes: the need for time to recover from prior surgeries, the notion that surgery requires additional surgeries, pain and side-effects, lack of control, and even death. Based on patients’ comments, it appears that while European Americans are mostly concerned with healing past surgeries before undergoing additional ones, African Americans are mostly concerned about the possibility of a transplant not working and being out of control.

The notion of being ‘cut on’ has been examined in other research, yet it conveyed a different meaning altogether. In a study of breast cancer among Southern African American’s, Mathews, et al., (1994) found that: “surgery was thought by 20 of the women interviewed to be



dangerous because, ‘cutting on a cancer will make it spread,’ and ‘once air gets to a lump it will make it grow.’” Here the phrase “cut on” is used but exposure to air is understood as a problematic agent to cancer specifically.

In both Mathews and colleagues’ study, and my study, a slight similarity exists in the sense that being “cut on” results in a form of increase, whether it be the growth of breast cancer as in Mathews and colleagues’ study or additional surgeries as among the case of dialysis patients in my study. Another similarity is demographic: the majority of patients who were concerned about being cut on in both studies were African American, some of whom were originally from the Southern states.

A common feature of the various meanings and explanations associated with not wanting to be “cut on” is that they were grounded in patients’ personal and social real life experiences. People who practice such experientially-based processes of reasoning, or who Gaines (1993) calls “natural empiricists,” have been described in other studies (Kaufert and O’Neill 1993; Gaines 1985a). While biomedical practitioners may acknowledge that transplant surgery is not without some risks, most would likely agree that the risks are worth the advantages of transplantation vis-a-vis dialysis. As Gaines (1993) pointed out, biomedical and lay conceptions of risk differ because the former are abstracted from statistical data while the latter are based on real experiences. This is particularly the case among patients who fear that surgery begets more surgery, for as Gaines (1993:7) noted, “it is these denied negative outcomes that may be foremost in the minds of lay, that is, natural empiricists.”

#### **Fear of Being Worse-off from a Transplant**

Half of the patients did not want a transplant because they thought they would be worse-off from a transplant. Patients who indicated this reason had a significantly higher income

than those who did not (\$16,042 vs. \$7,253) ( $t=2.297$ ,  $p=.038$ ,  $n=26$ ). There were also strong insignificant trends for gender and marital status to be related to this variable. First, more males than females tended to specify this fear ( $X^2=5.0$ ,  $p=.060$ , Fisher's Exact Test). Second, more patients who were separated, divorced, or widowed were more likely to specify this fear than married or single patients ( $X^2=7.619$ ,  $p=.055$ ). It is unknown why these patterns emerged, further research may be worthwhile.

Patients noted that they were content with their current health and well-being and did not want to disturb it by getting a transplant (e.g., Shirley, Dorothy). Three patients were concerned that they might die from the transplant. For other patients, a transplant presented more harm than good in terms of changes to a recipient's bodily state and lifestyle. These issues are discussed below.

#### Effects on the body

Four of these patients were concerned about the effects of a transplant on the body. All four were African Americans. For example, Anthony indicated that he had talked to several kidney recipients, most of whom had two to three transplants. What disturbed Anthony was that: "every time [someone] gets a kidney and it fails, they don't take it out." The idea of multiple kidneys inside of him was strange because of its effect on the body: "All those kidneys, it's a different reaction, it has to be a bad reaction." Another patient was similarly concerned about the effect of transplantation on the body but expected that the native kidneys would be removed instead:

Naomi: "[during transplantation,] when they take your old kidneys out and have to rely on a new kidney and if that failed, I'd have to rely on dialysis. I don't like that idea. If I get a transplant [there would] only be one kidney. If that don't work, you don't have anything."

Apparently, Naomi did not realize that people are on dialysis because neither kidney functions. Interestingly, she felt differently about transplantation if kidneys were kept inside of a recipient: “I would go for it then if I had [my] old kidneys.” Couching his concern in terms of his social experience with recipients, a patient related:

Lewis: “When I was in the hospital, a friend of mine I met here got a transplant. ...I guess, his head swoll up twice the normal size and they drained fluid from his brain.”

Another patient expressed his concern in hereditary terms by noting the

Michael: “possibility of some people developing sugar. It runs in my family. I took that into consideration and I didn’t want to get sugar... [With sugar,] they chop you up.”

Here, the patient makes reference to the risk of developing diabetes from a transplant, and the likely consequence of amputation.

### Rejection

Two African American patients framed their concern about being worse-off from a transplant in terms of kidney rejection. For example, patients stated:

Dorothy: “I heard so much talk about rejection. I got used to dialysis.”

Naomi: “I think it’s a lot to go through and then it fails.”

### Concern about Taking Transplant Medications

A major worry among almost half of the patients (46.6%) was the idea of having to take transplant medications. As Table 7.5 shows, the majority of these patients were African American (64.3%). There were no significant relationships between this variable and sociodemographics of patients. Patients asked to explain their concern often indignantly responded, “I already take a lot of medicines!” There were two main issues involved in taking medications: the side-effects and the dislike of taking more medications than a person was currently taking. These issues are discussed below.

## Side-effects

When asked how they felt about taking medications, some patients responded with general statements admonishing the side-effects of transplant medications:

Audrey: "I don't like it either. There are so many side-effects to them. They take care of one problem and it creates another."<sup>90</sup>

Based on personal, past experience, two African American patients voiced worries over the addictive quality of transplant medications, notably the steroid Prednisone:

Andrew (who was a previous drug addict) was primarily concerned about Prednisone because: "It's an experimental type drug." [EG: Why do you think it's experimental?] "Because they don't have any literature on it in the library. The literature I read says Prednisone affects bone marrow, is addictive, and has horrible side-effects." He also mentioned having heard a lot about Prednisone: "I'm afraid. It's very addictive, it affects your bones, you can't miss taking it, because if you do, your body goes through withdrawals -- like being on heroin. I've already gone through that most of my life. I don't want to anymore." Andrew was not concerned about taking medicines in general, "as long as they make me feel better."

Janet did not want a transplant because: "I was told I'd have to be on steroids. [They] give you steroids and it blows you up. [You] put weight on and I didn't need that. [You'd be] on it as long as you live -- take it as part of medications. It's a dangerous drug. [EG: Why?]" The fact you have to be weaned off of it, can't just stop. [The] body can't take a sudden stop. I didn't know too much about it. [When she had an infection in the past, she was] once on it for a little while -- a month [and it] disfigures [the] face, [making] the moon face, I gained 30 lbs. and I didn't want any more of this."

Other patients' reports of their discomfort with taking medicines were grounded in social knowledge. For instance, Anthony explained that he did not want a transplant because of "the after-effects of the medications you take to accept the kidney." He indicated being particularly worried about "all of them in general. I don't know enough about them... All I've heard is bad rumors about the after effects. I haven't heard anything encouraging." He had heard rumors that the medications give people "rawness in the mouth, itching, painful, swollen inside the mouth, irritable, raw spots in your mouth."

Another patient explained his consternation with taking steroid medicines with regard to their prevention of healing:

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<sup>90</sup> Interestingly, this view of medicines parallels the view of surgery noted by patients above that surgery leads to more surgery.

Malcolm: "You still have to take medicines even if it rejects... If you get a transplant and it fails, you still have to take medicines. It's rejecting. To get it out of me I need to take another transplant because they won't take it [the bad kidney] out... I know the body's constantly rejecting it. It makes a lot of sense but I'm stuck. But I have to take another transplant to get [the old kidney out]. I'm forced to be on the transplant list, no choice, I still need medicines."

Malcolm related his concern with needing to "take more medicine to keep from rejecting" with the fracture in his ankle. He was hesitant to obtain a transplant because of his understanding of how healing works as it pertains to the function of blood. He recalled from his undergraduate classes that blood has six different functions: it carries oxygen, water, and food, it removes waste and carbon dioxide, it forms clots, and it fights viruses. Malcolm also noted,

"But it can only do one thing at a time... It takes longer for the body to heal. The surgeons don't understand I'm not a normal person [since he has kidney failure]. It takes a long time to heal because of blood. If I drink a lot of fluid it's [the blood] full of water, and it goes to the lungs and I can't pass oxygen. When blood is full of fluid I'm short of breath."

Malcolm drew upon a friend's experience (who we'll call Ben) to drive the point home. Ben also had a bone fracture but when he got a transplant and took Prednisone, the fracture could not heal.

Malcolm thought that before doing the transplant, the doctors

"should have allowed the [Ben's] leg to heal first. A lot of people die-- they took too many operations at one time, or didn't ask enough questions of doctors. If blood is an intricate part of healing the body, something needs to be done to heal the body. If the body is strained to heal, it leads to another infection, if it doesn't heal."

This patient's thoughts about medicine and transplantation also illustrate the incorporation and personal modification (via own or others' experience) of medical knowledge into patients' treatment decision-making process. In addition, it is interesting that this patient (and other patients throughout this chapter) do not seem to refer to their own physicians about medical information, e.g., "my doctor said I need to consider all the side-effects of transplantation."<sup>91</sup> Rather, patients strongly referred to their peer group, as indicated by the reliance on "rumors" and other patients' comments about transplant side-effects. Patients'

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<sup>91</sup> I thank Laura Siminoff for making this distinction. She notes that the lack of reference to physicians about medical information is unusual.

socially-generated medical understandings of transplantation and dialysis are likely a matter of dialysis being a public treatment. In fact, it is the only medical treatment in which patients receive it together, without privacy, quite like the ward system in place thirty years ago.<sup>92</sup>

#### Taking more medicines than one is currently taking

The amount of medication dialysis patients take on a daily basis depends on the nature of their kidney disease. For instance, patients need medications to control their blood pressure, and phosphate-binders and calcium supplements to allay bone deterioration, etc. To give some perspective on the quantity, recall from Chapter 5 that patients usually brought all of their medicine bottles or a list of their current medications to the nephrologist at their clinic visits. The number of different medicines patients took ranged from approximately five to fifteen, and some of these were to be taken more than once per day.

In contrast, transplant recipients must take two or three different immunosuppressants and other medications several times per day to ensure that the kidney does not reject. For example, a transplant recipient on the Internet said she takes nine different medicines, three of which are immunosuppressant drugs, for a total of eighteen pills, twelve of which are immunosuppressant drugs. Recipients must therefore take transplant medications in addition to several medications taken during dialysis. But what some dialysis patients may not have realized is that they would need to take their calcium supplements and other medications that mitigate against the damage of kidney failure/toxins for the rest of their lives. Some patients did not consider taking medicines as part of their everyday lifestyle:

Francine: "I'm not a medicine taker anyways."

Dorothy: "I have to be on more medicines. I never took medicines until I got on dialysis. I'm not a medicine taker."

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<sup>92</sup> It is likely that treatment is done in a public arena because it is publicly funded. Patients are not treated as private patients perhaps because they are not paying for the privacy. As Laura Siminoff pointed out, even patients undergoing chemotherapy in one room together are afforded privacy through wall dividers.

For patients who do not like taking medicines, the prospect of taking even more, and for the rest of their life, becomes intolerable:

Shirley: "Most important, I don't want medications. I don't know what... I take enough medicines as it is...get drugged out." (In the second interview, she explained further): "I have heard when you get a transplant, you still have to go back and forth to the clinic and take more medication." She emphasized that she *already* goes to the clinic and *already* takes medicines, and chimed: "I don't want to add no more. I take enough medication."

Virginia: "It's too much, all that medicines you have to take. I just don't like taking medicines. Most people taking medicines are more sick, are always sick, there's always something wrong with them... I take enough medicines and I never was a medicine person. So I don't think it's [a transplant] worth it to me. Dr. B. had me on so many pills, so I didn't even take them. The labs came back OK. And he got upset with me... I hate taking medicines. My family never took a lot of medicines. If we had a headache we'd take aspirin." She then recounted how her grandmother in Georgia used to prepare herbal teas for her when she was sick which always worked.

Roland: Originally he had considered a transplant because "I was told that a transplant wasn't as time-consuming as dialysis... I had always thought that transplantation would bring you back to the way you were but it's not so." He "thought transplantation was a cure-all" but people told him about the medicines. Consequently, he thought that transplants "sounded as much trouble as dialysis [because he'd have to] take medicines the rest of my life [and] the possibility of my kidney not taking." He did not know that with a transplant he would "have to take medicines for the rest of my life." He was not interested in that because "I don't want to give any of my time to something I don't want." And, he did not want to be 'monitored' in terms of the medicines, commenting, "It took so long to adjust to this." Resigned to this fact, Roland concluded that he was '100% for a transplant if I hadn't heard about the medications."

We can deconstruct the concern about taking many medications held by more African American patients than European American patients by drawing upon the African American folk notion of the body as elaborated by Snow (1991) and by Marks (1998) discussed above. Marks' African American informants believed that medicines could cause breast cancer. They were suspicious of their side-effects, the lack of information about the effects of medications on their body, and the what the medications were made of. Again, with reference to the whole body notion, Marks writes: "If medicine was powerful enough to relieve pain in one part of the body, it was probably doing something else somewhere else" (1998:320). Similarly, dialysis patients in this study may have been suspicious about taking medications because they are biomedical interventions, and thus cause "unnatural processes" to occur in the body. Certainly, they expressed concern about the prospect of the side-effects of transplant medications, which are, in fact, quite formidable.

## Lifestyle

While one patient's concern about taking transplant medications was mentioned in relation to lifestyle changes resulting from a transplant, it is appropriate to discuss it here. This patient, Michael, explained how his lifestyle would change by being required to take pills: "Just thinking about [a transplant] I wouldn't want to take all those pills, trade a handful of pills for a bucketful. I don't remember to take pills--that's why it would be a waste." Michael mentioned that he might get into a "mood" of "being tired of taking his pills," and that some of the pills he takes now are "bigger than your throat!" In addition, he did not "want to carry them around with me" not because it was embarrassing, but that he was a free-spirit who wanted to take only what was in his pocket wherever he went. Michael affirmed that he did not like the appearance of being a "junkie." He had learned about the increased number of pills taken from talking with other patients about transplantation. This patient's perspective serves as a useful case study of personal and social issues pertaining to medicine taking that patients sometimes deal with.

Patients' dislike of the idea of taking additional medicines may stem from biomedical and US cultural beliefs in the general population about taking medicines (see Zborowski 1969). In Medicine and Culture, medical journalist Lynn Payer (1988:125) writes that American doctors "often eschew drug treatment in favor of more aggressive surgery" because of the American biomedical tendency to treat in an aggressive way. Both American biomedicine and US culture are influenced by Puritanical values (Goodwin 1995) which may also inform dialysis patients' views about taking medicines.

A characteristic tenet of Puritanism is being pleasure-averse or asceticism; this is apparent in biomedicine's underutilization of narcotic analgesics in hospitalized patients (Cleeland, et al., 1994). Many healthcare professionals, patients, and non-patients (e.g., athletes)



in the US consequently view pain as good or noble; consider the phrase, “no pain, no gain.” We can draw upon such analyses to understand patients’ resistance to taking medicines. Notably, people may think that taking medicines makes one look “weak.”

Studies of epileptic and rheumatology patients’ medicine-taking practices in the US and in the UK found that people do not take their medicines for various personal reasons, including: a) patients did not want to be reliant on medicines since it reflects a person’s weakness, b) medicines did not fit into patients’ lifestyle (e.g., not wanting to be seen taking medicines among young patients - aged 18 and 23 years), and c) to minimize side-effects, etc. (Conrad 1985; Donovan and Blake 1992).

### **Fear of a Foreign Part in My Body & Religious Reasons**

One a priori hypothesis was that certain ethnic groups (e.g., African Americans) which have been known to resist the idea of organ donation because of predominant religious beliefs (e.g., ‘the body must be kept intact for life after death’<sup>93</sup>), would likewise be hesitant to accept a transplant for the same reason. This hypothesis was partly confirmed. Specifically, there was an insignificant trend for more African American patients than European American ( $X^2=3.982$ ,  $p=.068$ , Fisher’s Exact Test,  $n=29$ ) patients to indicate that they feared a foreign part in their body, in its various meanings, as a reason to not seek a transplant. In addition, those who indicated this reason were significantly younger than those who did not ( $t=-2.298$ ,  $p=.029$ , age 48.3 vs. 56.3).

The responses from the patients who indicated this reason for not wanting a transplant show that the meaning of ‘fear of a foreign part’ differs, in part, from the notion as reported in the donation literature. The meanings patients attributed to the fear of a foreign part in their body

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<sup>93</sup> See Chapter 4 for a discussion of this issue.

ranged from feeling eerie about it, religious views, concerns about kidney rejection, and a different form of reasoning about the necessity of transplant medications.

### Feeling eerie or squeamish

To further explore patients' fear of a foreign body part, patients were asked during the second interview if they felt 'eerie' or 'squeamish' (meaning uncomfortable or uneasy) about the idea of another person's body part in them. Few patients (n=3) stated that they would feel 'eerie.' Two of these patients were African American and one was European American; their religious backgrounds were Baptist, Protestant nondenominational, and Episcopalian. Two patients articulated their feelings about another person's organ in them:

Shirley: "I just don't want nobody's died (*sic*) kidney in my body... I know I got to die too... I don't want someone else's in my body. It would probably be no problem." She attributed her uneasiness to her "imagination." I asked if she would feel differently if her daughter donated, and replied that it would be "eerie even if it's my daughter's kidney [since it's still somebody else's]."

Marshall noted that he "mentally" "didn't want no body's body parts in me." He attributed this feeling to his father who felt the same way. "It's the way I grew up. I don't want body parts in me."

It seems as though two patients' comments reflected a temporal dimension to their concern: they needed to become used to the idea of another person's kidney inside of them, and this uneasiness would eventually be overcome. As it turns out, Marshall even changed his mind and decided to seek a transplant by the third interview.

### Religious views

Two patients explained their dislike of a foreign body part inside them in religious terms, that in part support the literature, as discussed in Chapter 4. One patient was a Muslim African American male, one was a Baptist Jamaican female.

Michael: "I don't think about it... You should leave here with what you came here with."

Barbara: "I don't believe in taking somebody's kidney that's passed. Whatever I have, even if it shuts down, that's it. It's God's reason for it to shut down." She said that maybe "He" wants her to slow down -- from the kidney failure. "I could get a transplant tomorrow and it could shut down again... I want to get off but I want my own

kidney to start functioning. What I was born with... God gave me my kidney and if it shuts down, that's it." She elaborated how she "wouldn't feel right" taking a body part from someone else because her blood pressure is high and would remain high even after a transplant so that it would damage the kidney and "waste it."

Only two African American patients explicitly noted that they held religious convictions for not wanting a transplant. One was a Jehovah's Witness, the other was a Baptist. Jehovah's Witnesses believe that blood transfusion is forbidden to them by Biblical passages (Singelenberg 1990).<sup>94</sup> Jehovah's Witnesses wish to respect life as a gift from the Creator by not taking in blood to sustain life (Watch Tower Bible and Tract Society of Pennsylvania 1990:6; Dixon and Smalley 1981). The Jehovah's Witness patient stated:

Audrey: "I don't want anyone else's body parts in my body because of blood. Our body parts are kept up through our blood. The blood keeps it functioning. I don't want another kidney. It may not work for me."

She was also concerned about getting a disease through a transplant, such as AIDS or Hepatitis. Audrey's fear of catching an infectious disease again shows how this patient (and likely others) incorporates medical knowledge into their treatment decision-making process. This patient said that religion influenced her decision against transplantation "partially" and qualified it by saying that Jehovah's Witnesses do get transplants but it was a decision she had made on her own. She elaborated how religion influenced her:

Audrey: "There's a thing about the blood issue. Organs function from the blood in the body. The blood would be in the kidney. Scriptures tell us not to eat the body. [Getting a transplant would be like] feeding on someone else's blood. It's a selfish thing of me to ask of my family or others to give me what God gave them to survive. I had my kidney. There's a chance they'll end up just like me." Shaking her head no-way style, this patient concluded, "There's no *guarantee* that your kidney's going to work. I'm not going through all that surgery and all that [unclear] and all that hurting for nothing" [emphasis added].

The Baptist patient, Malcolm, related: "I believe God will help me. I've seen people recover." He was making reference to watching a televangelist. Malcolm indicated that religion

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<sup>94</sup> Biblical references admonishing the use of blood are the following: In one passage, the Creator declared: "Everything that lives and moves will be food for you... But you must not eat meat that has its lifeblood still in it" (Genesis 9:3-6, *New International Version*). In addition, when the Creator gave the Torah to ancient Israelites, he avowed: "If anyone of the house of Israel or of the strangers who reside among them partakes of any blood, I will set My face against the person who partakes of the blood, and I will cut him off from among his kin. For the life of the flesh is in the blood" (Leviticus 17:10, 11, *Tanakh*).

was very related to his decision to not obtain a transplant because he had “faith that I’ll feel better.” He did not want to be “double-minded” since Scripture warns against that, in terms of not wanting to have the faith that God will heal him and then also getting a transplant. He explained how he went to church and asked for prayer, he realized that he had to learn another step: his children prayed for a transplant for him but he didn’t want a transplant. “You pray for what you think I need, not what I want.” He believed that people need to be careful with what they wish for and related the story of how his wife and he went food shopping and saw another couple shopping with two large carts full of food and good meats, and paid for it all with food stamps. Then his wife said, I wish we had food stamps, and then soon after they were out of a job. This example reflects a sense of cause and effect which is tinged with fatalism. In summary, this patient’s approach to transplantation reflected a similar philosophy.

### Fear of kidney rejection

For three African American female patients, the concern with a body part in them had little to do with squeamishness or religion, but rather with the possibility of kidney rejection. Their comments were as follows:

Virginia: “People with body parts reject. It’s not really worth it- rejection, to go through all over again, get your hopes up and dashed down. I worked this [dialysis] into my lifestyle.”

Gloria: “The tests may say the kidney is right for you and then it rejects and go back on dialysis. I’m thinking about surgery, pain. If I don’t have to I’d rather leave it alone and not do it [transplant]... If I go through all the tests, get a transplant, and in six months it rejects, I’m back on dialysis again.”

Dorothy: “You don’t know whose kidney you’re getting. They try to match it as much as possible. Science is great but not that great.”

### Patients’ unique form of logical reasoning

Two African American patients (one Muslim, one Baptist) explained their reluctance to have another person’s body part in them through their own logic about the necessity of taking transplant medications. They believed that a good working kidney transplant shouldn’t need

drugs to work; if they need the drugs, then the kidney must not be very good. This reasoning is reflects different assumptions about transplantation and organ receptivity. Patients expressed their views in the following ways:

Donna: "Someone else's [kidney] doesn't seem right. I have to take medicines so it doesn't reject. Why should I take medicines so that it works?"

Michael: "If I have to take all those pills to prevent rejection, it [the kidney] has no business being there. That's the major thought right there."

### **Fear of Death**

The fear of death was cited by almost a fourth of all patients (23.3%) as a reason why they did not want a transplant. Significantly more males than females specified this fear ( $\chi^2=7.950$ ,  $p=.009$ , Fisher's Exact Test). All of these patients were African American and Baptist. This fear implicitly permeates throughout many of the other reasons patients offered. The anxieties articulated by one patient are representative of the concerns voiced by many others:

Lewis: "I shouldn't be [afraid of death] because we all have to do it, but also I know two guys that had a transplant in January and both were afraid of a transplant and both died a week later after the transplant. So it's a catch-22 situation." He noted how one guy was on dialysis for fourteen years, the other for seventeen years. "I want a transplant, but I know I have to die. If I can last on dialysis two more years, I want to see my daughter go to college, then after I might consider a transplant." This patient explained that before he knew about dialysis he believed "that I had to have a transplant. I don't mind so much about coming to dialysis. On top of being scared of transplantation, it's scary for someone to say get a transplant, but what if I die?"

Like the patient above, many were simply afraid of their life potentially ending even though they wished to continue to live by getting a transplant. The fact that European American or non-Baptist patients did not express fear of death may be attributed to two factors. First, the remote nature of the threat of death at the time of the interview may have lead to a low percentage of patients expressing fear of death (Taylor 1979 in Marks 1986). Second, some patients may, in fact, be afraid of death, but not express their fear during the interview because of religious-based notions of behavior. For example, it is common for Catholics (who were all European Americans) to be stoic in the face of adversity (McGoldrick 1991). Indeed,

“American” attitudes toward death can be characterized as “death denying” as death has come to be expelled from the common, everyday experience (Feifel 1977). In contrast, Baptists and/or African Americans were the only ones to explicitly express their fear of death perhaps because it is more common or acceptable for African Americans to be openly expressive about death (Devore 1990; Hines 1991). While one study found that “black” elderly males display the greatest death anxiety (Myers, et al., 1980), another study found that “blacks” are less afraid of death than “whites” (Reynolds and Kalish 1974).

### **Do Not Want to go through all the Tests to get on the Transplant Waiting List**

Patients cannot be put onto the transplant waiting list by simply asking for a transplant, as a few patients believed (e.g., Cecelia).<sup>95</sup> Patients must endure a rigorous series of physical and laboratory tests that determine whether a patient is medically and physically suitable for undergoing the physically demanding surgery. Patients being worked up for a transplant are required to take several procedures and tests as listed in Table 5.1. One third of all patients indicated that they did not want to go through the testing to get onto the transplant waiting list. As we see in Table 7.5, most of these patients were African American (n=8) and most were Baptist (n=8), and the majority were female (n=6). There was an insignificant trend in which those who indicated this reason had completed fewer years of education than those who did not indicate this reason ( $t=-1.911$ ,  $p=.066$ , 11.2 vs. 13.1 years of school).

Two patients clearly voiced their thoughts on the matter:

Malcolm: “I don’t know why they have to do so many things” [referring to need to be tissue typed twice when his sister got tested] “it could be the money, again” [referring to his suspicion of doctors trying to get wealthy from patients].

Barbara: “[There’s] too much testing... even though you go through testing, you still got to wait.” To paraphrase, this patient believed that the waiting list was a waste of time since “there are so many people ahead of you.”

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<sup>95</sup> A patient who was selected but not ultimately recruited in this study also believed this.

### **Concern about Not Getting a Kidney from a Donor of My Ethnic/Racial Background**

Although only two African American Baptist patients (6.7%) indicated that racial differences in a potential donor may be of concern (Shirley, Anthony), only one patient articulated why. Anthony believed that ethnic groups are different in that their “diet is different, different diseases, side-effects of the organ in the body-- you’re made up of what you eat.” He elaborated on what he ate and how other people differ: “I’m basically a country boy-- I like country food [which is] fresher, not as many treatments to the food. Quakers have a good diet. Other groups eat things I’m not accustomed to eating.” This patient also noted how diseases that differ between races: cancer is one that others have, but people like him [African American] do not have cancer as “severe”... “Europeans have a lot of diseases, especially in the Mediterranean.” His experience in the military formed the basis of this observation.

Interestingly, another patient, Malcolm, had also commented on the relationship between ethnicity, food, and dialysis/transplantation. To improve his health Malcolm watched his diet and asked the dialysis dietitian many questions. He mentioned that he did not like that the dietitians were mostly “white” and the patients were mostly “black.” This was a problem because the dietitians handed out meal recommendations that were primarily of “white” foods that, this patient noted, “blacks” do not eat and can not buy at their local markets. African American patients, used to eating a “soul food” diet of collard greens, green beans, bacon, chittlings, were told by dietitians to cut down on fatty foods. Since “white” foods like lamb, turkey and zucchini were recommended, he made some of them for his children but they would not eat it. “Where the hell are we going to get it?” he asked himself. Malcolm recounted being in a “white” supermarket and asked a person who worked there, “where are the grits?” and was surprised by the reaction he received which suggested that the store did not carry them. The

difficulty in finding “soul foods” in middle class suburbs has been noted elsewhere (Hughes 1997).

### **Age: Too Old to Get a Transplant**

Seven patients (23.3%) indicated that age was a reason why they did not want a transplant. Although they were still within the age limit to get a transplant, these patients believed they were too old for it. Those who thought this way tended to be older than those who did not indicate this reason ( $t=2.906$ ,  $p=.007$ , age 61.9 vs. 50.8). In addition, there was an insignificant trend in which these patients had completed fewer years of education than those who did not indicate this reason ( $t=-1.873$ ,  $p=.072$ , 11 vs. 13 years of education).

Patients provided different reasons for thinking that they were too old for a transplant. Three patients gave medical explanations. One 50 year-old man stated how he did not like the idea of getting “cut on” or surgery at his age and stated,

Clifford: “I don’t think it’s worth it, not at my age. It just seems like so many complications. I’ve heard about all the medications, it’s a lot more extensive than what we have to do now. ... If I was 25 and it happened [he had ESRD] I would do it [get a transplant]. I’m not going to be here much long[er].”

In the meantime, Clifford did not want a transplant to “take up my time with the operation and medicines.” But if it could give him 50 more years, he would consider it. Naomi, A 65 year-old woman said that if she were younger, she would “be able to take it better” and “If I was younger, I’d take the chance. I stand a better chance with dialysis.” Only one patient, Francine, age 67, indicated that a healthcare professional told her that she was too old for a transplant. She reported that a nurse had told her “my age was getting against me.” She also noted, “I talked to a nurse about it [transplantation] and she said there’s an age limit of 72.”

Two patients offered another explanation that verges on being medically oriented but yet expresses disinterest in transplantation. They said that age was not the main concern because:



Francine: “I guess I’m not too old but pretty soon will be, but I really don’t want it. It’s the only answer I can give you” (age 67).

Pauline: “If I was younger I’d want a transplant... age might be a cop out... I don’t want to go through the surgery [at age 65]” (age 65).

Three patients explained that they did not need a transplant because they have lived a full life: “I already lived my life, honey,” noted 57 year-old Dorothy. Another woman, Naomi, aged 65, expressed an altruistic sentiment in her explanation that she would rather have younger people receive a transplant: “[There are] so many young people waiting for a transplant... I’ve lived this long and they haven’t had a chance yet.” She justified her sentiment by noting how her nephrologist “said people can be on dialysis for 21 years.” A 67 year-old patient, Elliot, believed that he was not going to live much longer anyway given his father’s length of life.

Patients who selected the card indicating that they felt too old for a transplant were asked if there was an age at which they would be more willing to consider a transplant. Their responses are listed in Table 7.6. The differences between current age and ideal transplant age range between 15 and 30 years.

**Table 7.6 Current age and ideal age to receive a kidney transplant**

Patient	Current Age	Gender	Ideal Transplant Age	Difference in Age
Dorothy	57	Female	30’s	~25 years
Pauline	65	Female	(would not give age)	N/A
Naomi	65	Female	40’s	~25 years
Francine	67	Female	50’s	~15 years
Clifford	50	Male	20’s	~30 years
Roger	60	Male	30’s	~30 years
Elliot	67	Male	40’s	~25 years

An interesting finding is that all seven patients who indicated that they were too old for a transplant were African American. When specifically asked if they felt that they were too old for a transplant (because they did not select the card), none of the European American con-transplant patients aged 50 and older (n=5), replied affirmatively, except one 63 year old woman at the second interview. This ethnic difference may be due to the likelihood that older African

Americans have witnessed more “race”-based medical practices than older European Americans. Older African American patients may therefore be more reluctant to put themselves in a position of potentially receiving “race”-based care during the transplant surgery and week-long hospital recovery.

In addition, significantly more patients who selected this reason were widowed, separated, or divorced than married or single ( $X^2=8.305$ ,  $p=.040$ ). As previously noted at the beginning of this chapter, this relationship may be due to the fact that older patients may fear undergoing surgery and recuperation without the support of a spouse.

### **I Have Kids and Need to Take Care of Them**

Two patients (6.7%) (Malcolm, Dorothy) initially said that they did not want a transplant because they have children to take care of. One woman believed that a transplant inherently involved having her children donate so she refused transplantation because it would interrupt their lives. This issue will be addressed later in the section on living-related donation. In contrast, a male patient had young children who took priority in his life over getting a transplant because he thought his kids were “under a lot of stress” with him being sick:

Malcolm: “I can’t take a chance of getting a transplant. The children need me right now... maybe if they’re grown.”  
... [My kidney problem is] secondary to watching the kids grow up... When they grow up I will concentrate on my well-being.”

### **EXTERNAL INFLUENCES ON DECISIONS TO GET A TRANSPLANT**

To fully understand how patients made their decision to seek a transplant, patients were asked whether other people -- healthcare professionals (HCP), family, and/or transplant recipients -- had any influence on their treatment decision making. Most patients ( $n=48$ ) (60.8%) stated that they had made their current<sup>96</sup> decision entirely on their own, without external

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<sup>96</sup> Some patients have been influenced by HCPs or family in the past when they had made different treatment

influences by either family or HCPs. The majority of these patients who made their own treatment decision were African American (77.1%). Yet some patients reported that their nephrologist (n=15) and their family members (n=28) influenced them to get a transplant. A few patients (n=11) (13.9%) were influenced by both groups of people; these patients were evenly divided by gender and ethnicity. Each external influence will be discussed below comparing pro- and con-transplant patients' experiences.

### **Healthcare Professionals**

Significantly more pro-transplant patients (n=13) than con-transplant patients (n=2) reported being influenced by their nephrologist or other healthcare professional in their treatment decision ( $X^2=4.773$ ,  $p=.038$ , Fisher's Exact Test).

### **Con-transplant patients**

Of the con-transplant patients, only two males (Anthony, a Baptist African American, and Edward, a Mormon European American) reported that they were influenced in their decisions by their nephrologist or other healthcare provider to remain on dialysis. This is not surprising given that most healthcare professionals believe that transplantation is a better clinical treatment and would thus not make recommendations against it. It was not what the healthcare provider said *per se*, but rather the nature of interactions that influenced both patients' decisions. Edward noted that his decision to not get a transplant was reinforced when he learned that the surgeon who had placed his fistula underwent a kidney transplant but died a year later. The other patient specified that the lack of communication about transplantation reinforced his decision:

Anthony: "I've had quite a few counseling periods about transplantation. They don't answer enough questions. I don't feel satisfied with the answers I get, they're not thorough enough."

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decisions (e.g., Lewis and Malcolm).

### Pro-transplant patients

Thirteen (26.5%) pro-transplant patients indicated that a healthcare professional, (usually their nephrologist or the transplant team) had influenced them to seek a transplant. These patients were evenly divided by gender, and the majority were African American (n=8). Ten patients were Baptist, two were Catholic, one was Holiness denomination. One of the reasons several patients noted was because the HCP directly told them that getting a transplant is what they should do. Statements that patients made to this effect are the following:

Louise: “[The nephrologist said] go for it-- it’s the best thing to do.”

Jan: “Dr. L. told me I should get one. He said I would feel better and my body won’t be as tired.”

While some nephrologists did not directly tell other patients to seek a transplant, some patients knew that it was what their doctor recommended. For instance, Allison related that whenever she spoke with her doctor, the nephrologist “always says, *when you get a transplant...* The way she says things, she expects I’ll get one and life will be better.” Another patient, Raymond, similarly noted, “I knew in the doctor’s mind that it was the way to go for me.” Other patients were influenced by talking with doctors about all that is involved in transplantation, perhaps being reassured of the process. One patient, Sam, was influenced by the fact that the transplant team told him about every step he will need to take to get a kidney and maintain one, the medicines, the types of pain, and that “they took the time to talk to me.” Siminoff and Fetting (1989) found that physicians’ recommendations are a strong predictor of patients’ treatment decisions for breast cancer.

### Family Influence

There was a significant relationship between being influenced by family members and patients’ treatment decision ( $X^2=20.454$ ,  $p<.0005$ , Fisher’s Exact Test). Specifically, more

pro-transplant patients (n=26) (53.1%) than con-transplant patients (n=1) reported to be influenced by their family members in their treatment decision.

#### Con-transplant patient

Only one con-transplant patient, Edward, was influenced by family members in his decision to remain on dialysis. The low rate of family views against transplantation is not surprising given that most patients have probably heard through the media that transplantation is a better clinical treatment for ESRD, and would thus not make recommendations against it. This patient, who was likewise influenced by his HCP, was also influenced by his wife, a physician. Edward's wife had both clinical and personal reasons for being against transplantation: she believed that he has been doing very well on dialysis over the past 17 years and that there was no reason for change. He stated, "She's deathly worried that something will go wrong -- I'll die or be worse off."

#### Pro-transplant patients

The pro-transplant patients who were influenced by their families to seek a transplant were evenly divided by gender. Slightly more of these patients were European American (n=13) than African American (n=11), and there was one Asian and one Lebanese. With regard to religion, almost half were Catholic (n=11) and Baptist (n=10), three were of other Protestant denominations, one was Jewish and one was Muslim.

Patients were influenced in two main ways. First, patients were influenced to seek a kidney transplant by the fact that their family member(s) had offered to donate (n=4). For example, Maureen said her family influenced her decision because "they were very positive about this -- they were willing to donate." Second, family members influenced patients by both offering general support (n=4), and telling patients that a transplant would make them feel better

(n=5).<sup>97</sup> One man, Ben, explained that he did not talk to his wife about transplantation but rather, “she talked to me! ... She’s the prime mover.” Another patient, Scott, recounted that his family “told me it would be better for me.”

### **Knowing Successful and Unsuccessful Kidney Recipients**

Another factor that influenced patients’ choices had to do largely with the social nature of dialysis. As described in Chapter 5, hemodialysis takes place within a group of people. Patients come to learn of each other’s dialysis schedule, health, and treatment choices. They talk to their neighbors or joke with patients seated across the unit, loud enough to be heard over the hubbub of dialysis pumps. Patients see empty chairs when others are late or sick or getting a transplant. Stories of patients’ experiences with a new transplant are passed along from staff to patient, patient to patient, and unit to unit. Rumors get started about how long people can live on dialysis versus with a transplant. Patients also see chairs filled again by the same patients who received a transplant only months or years ago. Given this context, it was therefore not unusual to hear that knowing (of) people who successfully received a transplant reinforced or even motivated patients’ decisions to seek a transplant; and conversely, knowing (of) people who received an unsuccessful transplant reinforced patients’ decisions to remain on dialysis.

Of all the patients in this study, 67 (84.8%) knew (of) at least one person who had undergone a kidney transplant. These patients were evenly divided by gender, and the majority were African American (n=45). On average, these patients knew (of) 3.7 people who had undergone a kidney transplant.<sup>98</sup> Of these transplant recipients, patients knew an average of 1.85

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<sup>97</sup> Since assessing the family members’ knowledge about transplantation was not a focus of this research, only patients’ reports of family members’ comments are noted here.

<sup>98</sup> Patients who indicated that they knew several kidney recipients (successful or unsuccessful) but did not specify the exact number were excluded from these analyses (n=8). Thus the exact count may be slightly larger than that presented in the text.

successful kidney recipients, and an average of 1.88 unsuccessful kidney recipients. Significantly more con-transplant patients than pro-transplant patients knew transplant recipients ( $X^2=5.278$ ,  $p=.025$ , Fisher's Exact Test,  $n=79$ ). Con-transplant patients knew, on average, significantly more *unsuccessful* kidney recipients than pro-transplant patients knew ( $t=-2.473$ ,  $p=.016$ ,  $n=59$ ) (2.6 vs. 1.3 recipients, respectively). Conversely, though not significant ( $p=.251$ ), pro-transplant patients knew, on average, more *successful* kidney recipients than con-transplant patients knew (2.15 vs. 1.5 recipients, respectively).

Patients were asked two questions about the influence of knowing transplant recipients:

1) Did knowing transplant recipients influence your treatment decision? and, 2) Did knowing *successful* transplant recipients influence your treatment decision? There was, however, no significant relationship between either question and patients' transplant status. We will now examine the extent to which knowing transplant recipients influenced treatment decisions first among con-transplant patients and then among pro-transplant patients.

#### Con-transplant patients

Con-transplant patients were primarily influenced by knowing *unsuccessful* transplant recipients. Many patients chose not to get a transplant because they have seen patients return to dialysis after an unsuccessful kidney transplant or heard that recipients died. Of all con-transplant patients, 16 (53.3%) indicated this reason for not wanting a transplant. There were two sociodemographic trends associated with indicating this reason. First, there was an insignificant trend in which more African Americans ( $n=15$ ) than European Americans ( $n=1$ ) specified this reason ( $X^2=4.535$ ,  $p=.064$ , Fisher's Exact Test,  $n=75$ ). Second, more men than women tended to select this reason ( $X^2=3.772$ ,  $p=.072$ , Fisher's Exact Test).

The theme emerged that for many dialysis patients, seeing is believing: unsuccessful transplant recipients are hard evidence proving that transplants do not work. Patients were influenced by unsuccessful transplant recipients in three regards: 1) by observing recipients return to dialysis, 2) hearing about recipients' experiences, and 3) by empathizing with recipients' disappointment of kidney rejection. Each of these issues will be discussed below.

### *Observing recipients return to dialysis*

Patients were influenced by seeing unsuccessful recipients return to dialysis in worse health than before they had left dialysis:

Naomi: "Since I've been coming here [dialysis center] I wouldn't want a transplant. Most of them still have to get dialysis after getting a transplant. Some people are in worse shape. Since coming here I've seen patients who had a transplant and are back on dialysis. So I don't see where it helped them... I wouldn't want to go through all that."

Lewis: Fed up with health professionals (including the research investigator) asking him about transplantation, Lewis exclaimed, "Everyone here had a transplant and it didn't work. Transplants don't work!" He also considered knowing 5 of 6 transplant recipients who died as "icing on the cake" for not wanting a transplant.

Clifford: "Most people have always had complications or it didn't work so I can't see putting myself through physical hardship."

### *Admonishments to not seek a transplant*

Some unsuccessful recipients had informed patients about their adverse clinical outcomes and warned them against seeking a transplant. These warnings by recipients had a strong effect on patients' treatment decisions, as the following statement shows:

Carl: said that knowing a handful of unsuccessful transplant recipients who all "had problems with it, ...they kind of discouraged me from it." He has had "negative readouts on it from everyone." An unsuccessful recipient told him, "If you don't have to do it, don't do it" and another who had been on dialysis for 14 years told him, 'Don't try to go for it as long as you're doing good.'"

### *Let-down*

Patients also were discouraged from getting a transplant because they empathized with unsuccessful kidney recipients' disappointment in returning to dialysis. Because the reason 'I do not want to go through the disappointment of a transplant not working' was inextricably bound to



knowing unsuccessful recipients, comments about that concern are included here. Five patients (16.7%) indicated that this potential disappointment was one of their concerns during the initial card sort task. Again, note how patients indicated their anxiety through the idioms of “chance” and “guarantee”:

Virginia did not want a transplant because she talked to people who had one and it failed: “If it failed I couldn’t handle it.” She described how some people get a transplant and then “suddenly it fails and they have to come back and start again... I’m not going through all that anticipation of hoping it will be a better life. Anything can happen and I’ll take my chances on dialysis.” She told the story of her friend who had a transplant but complications set in and she died at age 28. For other people, “after six months after the transplant it rejects and they end up back here waiting for another kidney.” This patient was overwhelmed by the idea of having your “hopes build up then dashed down. It would put me back in a state of depression.”

Janet described similar concerns with the let-down of transplant rejection by referencing patients with that experience. She knew a lady who had two transplants and both times it lasted only six months. She had to “go through surgery and it rejects, it’s all for nothing.” This patient heard from unsuccessful recipients that: “they weren’t happy about that... go through all that, made up [their] mind going through all that surgery for nothing, then the kidney don’t take. All that pain for nothing, all that excitement about getting a new kidney, hoping your life will change and then a big blow like that, you know... When they tell you that the surgery might reject, it don’t last that long 5-10 years, then you’re right back on the same thing.”

Andrew referred to one lady whose kidney lasted only five months: “I don’t want that disappointment. The sickness she went through. I don’t want to go [through that].” Regarding her experiences, he said, “She never felt anything like that. She was given rejection drugs and it made her sick. I can’t handle that.” He also knew three or four people with a transplant who are back on dialysis, and what they told him of their experiences, “none of it was good.” Andrew noted how they had to “go through a major operation, and a period of time of taking medicine. If it failed, I’d be really disappointed. I don’t want to go through the mental aspect unless I don’t have any other choice.” He would feel disappointed because a rejected kidney would “make me feel it was a last ditch hope. [I would] go through this major process, if it failed it would be a major disappointment.”

As these statements show, patients did not believe that kidney transplants work well enough to go through with the operation and possible eventual rejection. As noted in Chapter 3, the one and five year survival statistics for cadaveric and living-donor kidney transplantation, respectively, are: 93.7% and 79.9% versus 91.1% and 89.6%. These statistical data are considered by transplant professionals as strong proof that transplantation works. Yet patients’ tendency to disregard these statistical data is grounded in their personal experience of knowing numerous unsuccessful transplant recipients.

The finding that patients' treatment decisions are influenced by other patients' experiences is supported by other research. One study conducted a natural experiment by examining the impact of personal experience on ESRD patients' predictions about medical outcomes of treatment for kidney failure (McCauley, et al., 1985). Their sample consisted of four groups of patients: 1) chronic hemodialysis patients (n=19); 2) hemodialysis patients awaiting cadaveric transplantation (n=10); 3) successful cadaveric transplant patients (n=20); and 4) unsuccessful cadaveric transplant patients back on hemodialysis (n=10). A mailed questionnaire asked for estimates of the probability of various outcomes of transplantation and dialysis. McCauley and colleagues found that patients who experienced a successful cadaveric transplant gave higher estimates of transplantation success rates than did patients who experienced unsuccessful transplants. Another study found that the tendency to make treatment decisions based on one's personal experience of acquaintances who had already undergone treatment has been shown among women with early stage breast cancer (Charles, et al., 1998).

The work by cognitive psychologists on decision making (Tversky and Kahneman 1974, 1981) is helpful to explain why con-transplant patients were influenced by knowing unsuccessful kidney recipients. Tversky and Kahneman explain that in conditions of uncertainty, people make judgments about the probability of certain occurrences, in this case it would be kidney rejection, using heuristic devices. Based on their comments, dialysis patients appeared to employ some of the heuristics people use in everyday life. For example, according to the "representativeness heuristic," people's judgments about the probability (of kidney rejection) are biased by misconceptions of chance. Specifically, people expect that the essential characteristics of the process will be represented globally based on the small random sample of events they have witnessed. A notable component of this heuristic is the 'law of small numbers' in which people

credit small samples as being highly representative of the population from which they are drawn. In this regard it makes sense that dialysis patients expected kidney rejection to be more common in the ESRD population than it actually is after having met or learned about other patients who returned to dialysis. Patients' perceptions of the high likelihood of rejection are also influenced by the fact that successful transplant recipients do not return to dialysis. By applying the law of small numbers to this study (and that of McCauley, et al., 1985), we can understand how con-transplant patients have come to perceive transplantation as a futile therapy.

Another heuristic, the "availability heuristic," is even more useful in explaining the thought processes of dialysis patients. Accordingly, people assess the frequency of an occurrence, (kidney rejection) by the ease with which occurrences can be brought to mind. In this study, patients were able to call to mind, freely and without incentive, the patients whose kidneys rejected (often by pointing across the room). In addition, since "instances of large classes are usually recalled better and faster than instances of less frequent classes" (Tversky and Kahneman 1974:1127), patients who knew many unsuccessful transplant recipients were more likely to consider them. Lastly, the salience which people attribute to events is another factor affecting their ease of recalling certain events. Among dialysis patients, kidney rejection was seen as an important life and death situation that is expected to be highly disappointing, as discussed above. Therefore, it appears that dialysis patients used these heuristics as part of their decision-making process about their treatment for ESRD.

In contrast to the majority of con-transplant patients who were influenced by knowing (of) unsuccessful recipients, a few (n=6) (20.0%) patients reported that they were or would be<sup>99</sup> influenced by knowing successful transplant recipients. Specifically, these patients indicated that

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<sup>99</sup> If patients did not know any transplant recipients, they were asked if they would be influenced by knowing them. These patients are included in this analysis.

if they knew successful transplant recipients and had the opportunity to speak with them, they might be influenced to seek a transplant. Patients expressed this view in the following ways:

Gloria: talking to a successful recipient might change her mind and 'balance' out all the bad things she has heard about transplantation. "If I know more about it, it would put a whole other light on it. If I can go to a meeting and meet a person, if I have more information..."

Virginia: "If I knew people with successful transplants, and if they had a transplant for a while and was living a normal life, then I may start to consider it."

### Pro-transplant patients

Sixteen pro-transplant patients (32.7%) reported that they were definitely influenced (or their decision was reinforced) by knowing transplant recipients. Most of these patients were African American (n=11) and of Protestant denominations (n=13). In addition, 13 (26.5%) reported that they were influenced by knowing successful transplant recipients. The majority of these patients were European American (n=7) and African American (n=5), and there was almost equal representation among Protestants (n=5), Catholics (n=5), and other religious groups (n=3).

Patients were influenced in three ways. First, observing how well transplant recipients function in their everyday lives proved that transplantation can work. For instance, there were two transplant recipients, Martin and Tom, who were employed by two of the dialysis centers as technicians. Many dialysis patients (n=11) had established friendships with them and were influenced by hearing about and witnessing their successful transplants. Patients noted, for instance, that knowing these and other recipients influenced or reinforced their decision because:

Maureen: "They reinforced my decision after seeing how well they were doing."

Albert: "[Martin] looks like he's brand new."

Second, observing recipients and hearing about their well-being provided psychological comfort. For example,

Samuel: “[They] give me a lot more courage. It’s good to know someone is getting a transplant. It’s a long list. Hopefully my day be soon... . If they can do it I can do it.”

Third, patients were influenced by hearing about recipients’ positive transplant experiences. For example, patients relayed what their recipient-friends had told them:

Raymond: “If it works for you, you feel normal again.”

Louise: “The best thing to have is a kidney.”

Patients reported that they would also be influenced by knowing successful recipients and how long they had the transplant. According to Sandy, “It all depends on how long they’ve had it.”

The question we now face is, Why aren’t patients who are in favor of transplantation influenced by knowing unsuccessful transplant recipients, or the law of small numbers? Could there be a psychological stance that mediates the effect of this law? The work on social relations of sickness and health by medical anthropologist Arthur Kleinman (1980) may explain this anomaly. Kleinman argues that in addition to cultural reality, social reality is involved in the construction of clinical reality (1980:35). Social reality, as he defines it,

“signifies the world of human interactions existing outside the individual and between individuals. It is the transactional world in which everyday life is enacted, in which social roles are defined and performed, and in which people negotiate with each other in established status relationships under a system of cultural rules. Social reality is constituted from and in turn constitutes meanings, institutions, and relationships sanctioned by society” (Kleinman 1980:35-36).

One answer to our question can be found in the following quote:

“The tremendous power of social reality is in large part due to this fit between inner (personal) and outer (social) beliefs, values, and interests. It fashions a world we accept as the only ‘real’ one, commit ourselves to, often passionately, and react to so as to shape our own life-trajectories” (Kleinman 1980:36).

In the dialysis unit, there may be two social realities but patients attend to only one of them. The choices of those who desire a transplant may be reinforced by witnessing empty chairs and hearing about those who are successful recipients. Moreover, the process of obtaining a transplant is a major life and death commitment, involving innumerable tests on one’s self and

perhaps even on loved ones should they hope to donate. Many patients passionately seek the lifestyle that a transplant can provide, most notably, freedom from constraints of time and place. Patients' motivation to seek a transplant (an important theme for transplant professionals as later described), increases as they wear out from the dialysis lifestyle. Given this illness experience, it is understandable how patients who desire a transplant can set their minds for such a goal in the face of tragic evidence of its inconsistent outcome.

There were 21 (42.9%) pro-transplant patients and 17 (56.7%) con-transplant patients who asserted that they were not or would not be influenced by knowing (of) either successful or unsuccessful transplant recipients. Interestingly, six pro-transplant patients and three con-transplant patients<sup>100</sup> dismissed social evidence to the contrary of their view of transplant outcomes, noting that other patients' bodies are different from their own, and thus cannot be generalized. In other words, these patients explained their view in terms of the inappropriateness of generalizing the clinical experiences of other patients to themselves because patients have different medical problems and ways of taking care of themselves. Do patients who are pro-transplant tend to dismiss poor outcomes more than con-transplant patients? Consider the following comment:

Roland: "That was his thing. It doesn't have to be the same with me. ... We're individuals, one thing happening to one person doesn't necessarily mean it will happen to the next."

Patients also made reference to recipients causing their own kidney rejection as the basis for not being influenced by knowing (of) unsuccessful transplant recipients:

Talmadge: "He probably neglected [himself] because he didn't come to dialysis."

Joshua: "I didn't pay much attention to her [because] maybe she didn't do the right thing that the doctor told her to do."

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<sup>100</sup> All three of the con-transplant patients either had at one time been in favor of transplantation or had changed their mind during the study.

Danielle: "He didn't do what he was supposed to do [since he drank alcohol]."

Other patients (n=4) affirmed that they were not influenced by transplant recipients because they had already made up their mind about their treatment. For instance, Clarence stated, "[They told me that they] feel better, life is once again good... I was full steam ahead whether they had a positive experience or not."

According to Psychiatrist Rege Stewart (1983), the most devastating experience for dialysis patients is the death of another patient with whom they have identified. Stewart explained that patients use rationalization as a defense mechanism to ward off depression following the death of another dialysis patient. They rationalize that the other patient died because he was older, sicker, less compliant. The comments made by patients above suggest that they might have been rationalizing other patients' unsuccessful experiences with kidney transplantation to justify their treatment decision. This section has shown that patients' reasoning process guiding their decisions is informed by their social experiences during dialysis treatment.

#### PATIENTS' PERCEPTIONS OF THE FINANCIAL COSTS OF KIDNEY TRANSPLANTATION

Technically, all ESRD patients are entitled by Medicare to receive treatment in the form of dialysis or kidney transplantation. On the face of it, a patient's decision to chose one therapy over another should not be influenced by financial constraints. However, financial coverage for transplantation is in actuality limited, namely with regard to the purchase of immunosuppressant drugs. That these therapies are disproportionately covered calls into question the meaning of

entitlement or equal access to treatment regardless of financial capacity. It was therefore expected that patients' financial capacity would affect their treatment decisions.

The issue of financial influences on treatment decisions raises a controversial debate in medical anthropology. Recall in Chapter 1 that critical medical anthropologists (CMA) such as Marxists claim that Biomedicine replicates the capitalist class system through its organization and payment structure. Similarly, champions of the cultural critique of medicine would argue that limited financial coverage for transplantation by Medicare and Medicaid maintains ESRD patients' health problems (e.g., problems associated with dialysis) because such patients are unable to afford the difference in costs of transplantation. Thus, according to both groups of political economists, those who are poorest in society are the sickest because they are unable to afford treatment. Implicit in their view is that treatment decisions are at base financially determined. In contrast, cultural constructivists contend that cultural factors play an even more important role in treatment decisions (see for example, Hurwicz 1995, below). This section addresses this debate by delineating the limitations of CMA theory in light of ethnographic data from this study.

This section examines three financial issues. First, we examine whether and in what ways financial issues affect patients' treatment decisions to remain on dialysis or to seek a transplant. Second, various financial considerations are presented which can compound patients' treatment decisions. Lastly, this section discusses the types of measures patients take to maintain their kidney transplant in situations of limited financial resources.

### **How Financial Limitations Affect Patients' Treatment Decisions**

While all patients in this study voiced some concern about having too little money to maintain a kidney transplant, very few asserted that this limitation would prevent them from



seeking one. In fact, there was no relation between patients' income and their treatment decisions. Only a third of patients in the entire sample ( $n=29$ ) expressed concern about the costs of transplantation. There was a significant relationship between concern about the costs and ethnicity when comparing African Americans to European Americans ( $X^2=5.056$ ,  $p=.038$ , Fisher's Exact Test,  $n=75$ ). While the concern about costs was almost evenly divided between African Americans and European Americans, proportionally more European Americans (54.2%) than African Americans (27.4%) were concerned about the costs of transplantation. Income and ethnicity were not related. That African Americans expressed less concern may reflect their greater awareness that people can obtain some necessities without having sufficient financial resources (e.g., reliance on family, church, etc.).<sup>101</sup> There was also an insignificant trend for more pro-transplant patients than con-transplant patients to be concerned about the costs ( $X^2=3.724$ ,  $p=.060$ , Fisher's Exact Test). This trend may be due to the fact that pro-transplant patients will have to ultimately deal with financial issues while con-transplant patients will not. The fact that fewer con-transplant patients were concerned counters the CMA assumption that costs would be the main reason preventing them from seeking a transplant. We will examine these issues further by first considering the perspectives of con-transplant patients.

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<sup>101</sup> One might think that patients' lack of expressed concern over finances involved in transplantation may be due to a lack of awareness of the financial issues. However, it is doubtful that patients who are eligible for a transplant are entirely unaware for several reasons. First, upon initiation of renal replacement therapy, virtually all patients participate in a predialysis class. At AH, this class reviewed all three forms of therapy through a video and oral presentation. At that time, patients are also given several handbooks on the three treatments; financial issues are discussed in those booklets. Second, almost all patients have Medicare coverage for dialysis; it is basic knowledge that Medicare covers dialysis and transplantation. Third, dialysis social workers, nurses, technicians, and other patients intermittently speak to patients about financial issues involved in dialysis and transplantation. Fourth, the media commonly covers cases of transplantation and related issues. Moreover, all patients who have been placed on the waiting list or are in the process of doing so have already met with transplant professionals who discuss the financial issues. The key point here is that the extent of patients' awareness of financial issues is somewhat irrelevant given a mental standpoint in which people do not find it necessary to go through early financial planning when they have enough faith that various agencies exist to help them through it all.

### Con-transplant patients

There were only seven<sup>102</sup> (23.3%) patients who explicitly specified in any interview that costs were one reason for not wanting a kidney transplant. Only one person ranked costs as their most important concern holding them back from getting a transplant. Five of these patients were female and five were African American; not surprisingly, both females and African Americans in the US tend to fall within the lower socioeconomic strata (House, et al., 1990; Feinstein 1993). There were no significant relationships between those who selected this reason and their sociodemographic background.

Statements illustrating patients' concerns are as follows:

Beverly: "I don't have enough insurance to get [it] and you have to have it. I have to think about it... I can't do that right now because of insurance."

Although Anthony was concerned about the cost of a transplant, he did not know how much it costs, "but know it's quite an amount. I couldn't face the expense of it."

Roger commented that the medicines cost a lot, he could not afford it, and getting a transplant would be "a lot of headaches" (figuratively speaking). Although he did not indicate by selecting a card that financing a transplant would be a problem, Roger made it explicit with reference to being afraid of transplant medications. He feared: "it costs too much - I can't pay for all that."

Various patients, like Ginnie, also remarked that they had heard other patients say that the high costs involved in kidney transplantation held them back from seeking one. Yet the fact that only seven of thirty con-transplant patients indicated that costs were an important factor indicates that other factors took precedence in their decisions to not seek a transplant.

### Pro-transplant patients

Twenty-two (44.9%) pro-transplant patients expressed concern about the costs of transplantation. The responses patients provided about their financial concerns were limited. Several patients reported their fear of being cut off from Medicare. According to a male patient,

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<sup>102</sup> While only five patients indicated that costs were a concern at the first interview, seven patients indicated that costs were a concern at the second interview. The total number is used here for analysis as a more conservative way of testing the hypothesis.

Emmanuel: “The only problem with a transplant is they cut you off from Medicare... [I am scared of] being kicked out of Medicare after three years.” Emmanuel alleged that he is not concerned about the costs for the first three years since “they [the transplant professionals] told me that kind of stuff, it ain’t my business. I can’t do anything about it. They said not to worry about it. After three years I’ll worry about it.”

Of the 13 pro-transplant patients explicitly asked whether the transplant costs would prevent them from seeking a transplant, only two replied affirmatively (Sofia, Annette). Annette ultimately decided against transplantation solely because of being unable to afford the costs. In addition, only one of the pro-transplant patients, Hazel, indicated that the costs would prevent her from seeking a transplant. When Hazel spoke to her family about transplantation, “they was all for it until they found out about how much money it was. We don’t know how we’re going to pay for it.” She continued, “If insurance don’t pay for it, I will forget it.” To Hazel, paying between \$1,000 and \$2,000 per month on medications is “a lot of money to give up.” At a follow-up interview three months later, Hazel stated that she had talked to her insurance company and learned that it would be able to cover all the medicines; “that made me feel easy.” This case may represent other patients who believe that they do not have the financial capacity to obtain a transplant.

Transplant social workers reported that transplant costs have had relatively little influence on patients’ transplant decisions. According to these and other AH transplant professionals’ collective memory only two or three people have left the transplant evaluation process over the past year after learning of the steep post-transplant costs.

The vast majority of patients, however, were not very concerned about the costs of transplantation and would not let the costs prevent them from getting a kidney. The main reason patients reported not being worried about the costs is that they have commercial insurance in addition to Medicare. Even though they had insurance, patients were partly concerned because of the uncertainty of how steep costs will actually affect their lives, as Raymond stated: “[it’s]

always a concern because I don't know how it's going to shake out in the end." Two patients (Ginnie and Gina) reported that they were waiting for their husbands to retire for the new insurance to cover the medication costs. Ginnie noted that if her husband has not retired by the time she is offered a kidney, and "If I don't have the money, I'll just refuse it when they offer it." One patient, Jerry, even indicated that his family and friends would throw a benefit for him to raise additional money. In addition, patients' financial concerns were tempered by the fact that Medicare was going to pay for the transplantation and medications for three years. Considering the fact that the immunosuppressant medications are extremely expensive and that most patients are not employed, an outsider might find that patients' attitudes could be described as myopic, fatalistic, laissez-faire, and indicative of a state of denial. Comments supporting this view are:

Tammy: "I haven't thought about it. It hasn't crossed my mind. If there's a will, there's a way."

Andrew: "Medicaid will probably pay for that."

Roland: "I'm not going to pay for it. Dr. O said you don't have to pay for it... I'm not afraid of the cost of the medicines. I figure there's some way I could work it out."

Furthermore, patients expressed disbelief that the government could cut patients off from financial support following the transplantation because of its already significant investment in the welfare of dialysis patients. For example, 20-year-old Allison explained that, while concerned, she was not worried about the costs because she thinks it is "ridiculous" that doctors help patients to obtain a transplant but would not help her to support it. Incredulous about the three year cutoff, Allison remarked, "They're not going to give me [a transplant and let it go bad]."

Similarly, dialysis patients on the Internet engaged in lengthy discussions about the financial costs of medications and the government's willingness to let patients undergo kidney rejection because they cannot afford the medications. These patients could not understand how

the government could pay for a lifetime of dialysis for all ESRD patients yet not pay for a lifetime of transplant costs which would be significantly less than dialysis in the long-run.

Some of the patients' comments above suggest a limited understanding of Medicare's coverage policy. Patients talked about a three-year coverage but it is unknown whether they are aware that Medicare is responsible for only 80% of the transplant costs and of three of the most expensive immunosuppressant drugs. The lack of overall concern may be attributed to the possibility that patients have not been fully informed of the costs of immunosuppressive therapy during their evaluation process at the transplant center. Some of the patients were still in the process of being evaluated at the transplant center.

The fact that concerns about the costs of transplant medications were not expressed by the entire or even a large portion of the study sample means that other factors played a stronger role in decision making for treatment of ESRD. These data are important theoretically because they prove contrary to what some critical medical anthropologists would expect -- that financial issues and social class dictate people's behavior including access. Rather, social and cultural considerations hold greater weight in people's decision-making process.

One reason why many patients did not express profound concern about Medicare cutting their support at the third year post-transplant may be due to the fact that many patients are so desperate for any time off of dialysis that they would be content with a kidney transplant that lasted only a short period of time, within the Medicare coverage period. Data lending support to this contention are based on a question asked of pro-transplant patients: What would be the minimum number of years of a kidney graft lasting for it to be worthwhile going through for you? After patients provided a number, they were asked to state why they chose that number of years as the limit. Of the 49 pro-transplant patients asked, 40 responded in a numerical way for

calculations to be done. The mean number of minimum years amounted to 4.76 years. Also notable is that eight patients said that they would undergo a transplant even if it worked for only one year. Nine patients offered responses to this question that could not be included in calculations, for instance, patients selected “a day” (n=3), “whatever you get out of it” (n=1), “my whole lifetime” (n=1), and “I don’t know” (n=4).<sup>103</sup> People qualified their responses in ways that revealed their desperation to get a transplant, such as the following:

Richard: (1 day) “I truly hate this!!!”

Arthur: (1 year or more) “It takes almost a year for the medicines to get it straight... to get adjusted for the first three months. It takes a year to be [adjusted].”

Monique: “Two years is enough time to really feel how it’s to be without dialysis.”

### **Financial Issues Compounding Treatment Decisions**

Financial limitations can adversely affect patients’ capacity to seek and maintain a kidney transplant. One empirical study found that patients with a low income were more likely to experience allograft failure after one year and five years of graft function than were patients with an adequate income ( $p<0.01$ ) (Kalil, et al., 1992). The investigators identified patients with a low income level as those receiving medical assistance at the time of transplantation and for at least one year following. The investigators of that study failed to explain their findings though it is likely that individuals with a low family income run out of resources to afford immunosuppressant medications sooner than those with an adequate income.

Employment is a major financial issue compounding treatment decisions. Patients face many barriers to finding employment before and after transplantation. Very few dialysis patients are employed (USRDS 1997). Studies show that only 11%-24% of dialysis patients are currently working either full- or part-time (Evans, et al., 1981; Kutner, et al., 1991; Simmons and Abris

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<sup>103</sup> Twelve patients on the Dialysis Listserv also provided their views on this issue. They selected ‘any time’ (n=1), ‘1 year’ (n=4), ‘2 years’ (n=3), ‘3 years’ (n=1), ‘5 years’ (n=2), and ‘9 years’ (n=1).

1990). This is the reversal of pre-dialysis statistics, whereby before dialysis 75% are employed. However, 20-33% of the unemployed patients of working age maintain that they are both able and willing to work (Kutner, et al., 1991; Simmons and Abress 1990; Evans 1991). Further, dialysis patients tend to have lower educational levels and lower income levels than the general population (Kutner, et al., 1991). The United States Renal Disease System conducted a random survey of the employment status of new hemodialysis and peritoneal dialysis patients on about day 60 of ESRD (USRDS 1997). The results are presented in Table 7.7.

**Table 7.7      Employment status of hemodialysis, peritoneal dialysis (n=2400), and transplant patients (n=3245)**

Employment Status	Hemodialysis <sup>1</sup>	Peritoneal Dialysis <sup>1</sup>	Transplant <sup>2</sup>
Full Time	10.1%	24.7%	45.8%
Part Time	3.1%	7.0%	5.3%
Keeping House	9.0%	1.0%	N/A
Other	10.3%	5.6%	14.5%
Looking for Work	4.2%	2.8%	0.6%
Retired	9.4%	7.3%	8.2%
Disabled	53.5%	41.6%	12.6%
In School	0.4%	1.0%	N/A
Unknown	N/A	N/A	20.2%

1. Source: UNOS 1997d.

2. Source: UNOS 1998g. Two-year follow-up for cadaver kidneys in 1995.

As Table 7.7 shows above, only about 51% of patients are employed post-transplant (UNOS 1998g). Most people return to work following a transplant if they had one prior to transplantation, notes George, a transplant social worker. Employment is necessary in order to afford the 20% of costs of immunosuppressants for the first three years post-transplant and then the total costs following the three year mark. Patients need to find employment that offers benefits to cover these costs, since otherwise, they will be unable to afford the transplant. George also stated that patients who are young and less educated are less likely to find jobs that offer benefits, and may resort to employment at companies without benefits, like McDonald's. Even patients with marketable skills have difficulty finding employment following

transplantation because many companies do not want to provide the benefits for medications. At an annual review meeting, a patient considering a second transplant explained: “It’s hard to get a job with benefits. It’s hard because I can’t get insurance because of preexisting medical problems. Companies don’t want someone who’s sick.” This same patient noted that it is too difficult to find work that earns enough money so it is easier to remain on disability: “I know a lot of friends who want to work but can’t because the [cost of] medicines is so high and we have to eat and live.”

Although the Americans with Disabilities Act (1993) has made discrimination against people with disabilities illegal, even in the context of employment, patients reported that discrimination still occurs. Some employers require prospective employees to take blood tests for drug/alcohol abuse for insurance purposes. Such tests can easily reveal kidney problems and thus discriminate against people with ESRD seeking work. One patient, Mindy, recounted her unfruitful experiences seeking employment. Mindy had gone for an interview at a department store and received positive feedback from the managers. At the second interview, when she informed them of her kidney disease and the need to schedule hours around her dialysis treatment, their demeanor turned sour and she was not hired. Another potential problem that employed transplant recipients may face is when their job insurance changes and stops covering the costs of immunosuppressant medications. Dr. Ingel reported that this problem led to kidney rejection in some of his patients.

There are many physical and psychological barriers to rehabilitation for dialysis and transplant patients. These barriers include: a) the physical ability to work, b) barriers in the employment system, and c) the role of attitude. A study sponsored by Amgen, a pharmaceutical company, examined these barriers to rehabilitation among 359 working age dialysis patients



(Renal Rehabilitation Report 1994). The Amgen study found that illness or comorbidity was not a factor preventing patients from returning to work since the health of working and unemployed patients in the study sample was comparable. In terms of the employment system, the study found that both employed and unemployed patients affirmed that employer discrimination, access to private insurance, and fear of losing disability benefits were major deterrents to returning to work. After a nine month trial work period (a month in which at least \$200 is earned), the patient earning \$500 per month is considered gainfully employed and loses the disability.<sup>104</sup> It is very difficult for patients to receive disability benefits when their health worsens after returning to work. Further, the Amgen study found that attitudes differed between employed and unemployed patients: the former maintained that all dialysis patients should work while the latter believed that dialysis patients should not be working. Lastly, the study confirmed that patients who have more education are more likely to be employed. There is evidence that the vocational rehabilitation success rates for dialysis patients are lower than those for any other disability group (Life Options Council 1994:5).

Dialysis social workers explained further why patients cultivate attitudes against returning to work. According to one dialysis social worker, Erika, many patients get into what she called a “sick mentality” in which patients do not want to return to work even if they have the physical capacity to do so. In other words, patients are stuck in a thought process whereby the thought “I can’t do that, I’m sick” crosses their minds whenever a challenge arises. Evidence of this pattern is apparent when a social worker asks patients what they do in their spare time and many go out with friends at night, socialize, and go to clubs. When Erika tries to get patients to realize that they can return to work, many patients become irritated with her. She thinks that patients

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<sup>104</sup> Comments from patients in this study, from social workers, and the literature suggest that some patients are unaware of the trial work period and believe that employment entails the immediate cessation of disability benefits.

perceive that their therapeutic needs are limited to dialysis without additional psychosocial therapy. Another dialysis social worker, Brian, noted that when transplant social workers inform dialysis patients of the insurance issues and payments necessary to maintain a kidney, patients may find such information too complex and threatening since some have not had experience with paying bills.<sup>105</sup>

There are other financial issues that can compound patients' treatment decisions. Patients who live far from a transplant center, (e.g., several hours drive) may be at a financial disadvantage because of the costs of transportation, temporary room and board, as well as time away from work. Another factor compounding this problem is that insurance companies dictate which transplant centers patients may go to. A nearby transplant center may not be chosen under the insurance plan, and so patients must decide whether to go to a distant center but pay the costs of travel, or go to the closer center but pay out of network fees, or to forego a transplant altogether.<sup>106</sup>

### **Desperate Measures to Seek and Maintain a Kidney Transplant**

Patients and transplant professionals have devised several strategies to maximize the life of the kidney when recipients have limited financial resources. One strategy is working 'under the table,' that is, without reporting income and paying taxes. The incentive for patients to work under the table is to earn extra money for immunosuppressant drugs while maintaining Medicare benefits. Otherwise, after patients become gainfully employed, they are no longer seen as 'disabled' and thus in need of governmental support. A patient who received a transplant

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<sup>105</sup> It was not clear whether Brian was referring to medical or all kinds of bills.

<sup>106</sup> Further research should examine patient decisions in these types of situations.

lamented this fact to a transplant coordinator: “If I wasn’t working, everything would be paid for.”

A representative of Life Options Council, an organization that helps rehabilitate dialysis patients, said that patients engage in working under the table in some South East metropolitan areas more often than patients are reported to work on the books (Personal communication, Beth Witten 5-5-98). The employment status “other” in Table 7.7 may reflect this relatively high rate of under the table employment. Even transplant coordinators recommend patients work under the table to earn extra money to pay for medicines. This practice has been found to occur among other transplant patients (Abraham 1993) and impoverished mothers on welfare (Edin and Lein 1997).

Another practice patients and transplant professionals engage in entails the following exchange. Patients whose immunosuppressant prescriptions change sometimes bring their old medicines to the transplant center and the transplant professionals dole them out to other patients who need them but cannot afford them. In addition, transplant professionals and patients reported that dialysis and transplant patients “stretch” their medicines to make them last over time until another check arrives. Patients do this by taking one pill every other day instead of every day. Further, some kidney recipients form relationships with other transplant recipients who help each other by sharing immunosuppressant medications. A patient at an annual review meeting recounted how “if you stay around people with a transplant, we borrow medicines from friends if we can’t get the spenddown right away.”

Patients also intentionally get divorced on paper or remain permanently engaged so that the patient in the couple can get Medicaid.<sup>107</sup> This practice occurred in the case of one patient in

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<sup>107</sup> See Chapter 2 for data on Medicaid reimbursements for individuals compared to couples.

this study (Juliet), and has been documented elsewhere (Abraham 1993). Such couples are deprived of other social and economic benefits of marital status in the US because of limits in Medicare and Medicaid's coverage policy.

Another means of financially aiding patients with the high costs of medicines for comorbidities such as hypertension, diabetes, and immunosuppressant drugs is by seeking grants and awards from various foundations and organizations. A transplant social worker said that funds from the National Kidney Foundation, for instance, are drying up because there has been an increased need of their support over the years. Patients are also advised to seek aid from pharmaceutical companies. However, Dr. Alland explained the inherent problems with doing this:

"The suppliers of various medicines... will tell you that they have indigent patient type things where you fill out a form and they send a month's supply of medicines. But then you have to recertify and redo and it's such a bureaucratic pace to it that it is not a workable program. They can hawk it as they go around and talk to people and say they do have a program. But then when you find out the program is so onerous that it is beneath the practical achievable limits, it's nonsense."

A patient in this study (Richard) was disgruntled by the fact that his order for a free month's supply of medicine from a pharmaceutical company arrived a year after he had applied for it. These efforts on the part of transplant recipients indicate that there are ways, albeit difficult and frustrating, to make the kidney last without having resources of one's own.

In sum, many, if not most, ESRD patients must contend with financial limitations. The data show that the costs involved in transplantation are not a significant factor preventing con-transplant patients and even pro-transplant patients from seeking a transplant. These data are important for showing the limits of CMA's view of economic determinism. Let us briefly outline the model CMAs use to come to their conclusions and examine why these data contradict it.

The idealized capitalist world that Marxists delineate does not exist. The problem with their model of capitalism, as these data show, is that it does not take account of the realities of various cultural relationships that supply people with health care directly or the money to obtain it. Of the 79 patients interviewed, 52 (65.8%) were unemployed and thus not self-sufficient enough to afford the expensive immunosuppressants alone. However, 63.3% of all patients indicated that they were not concerned about the costs because “they’ll find a way” to maintain a transplant despite these high costs. Such patients expected the government, physicians, religious institutions, family and friends,<sup>108</sup> and fund raisers, etc. to provide a sort of ‘safety-net’ to insure the ongoing success of their kidney transplant. By this token, patients hoped to therefore find another way to meet their health care needs when they lack their own monetary measures. Thus patients’ practices fail to fit into the Marxist model of access to health care as being determined by financial capacity or class standing (e.g., Waitzkin 1980). The lack of concern about finances in treatment decisions may have been cultivated especially among ESRD patients because they are the only group of patients entitled to public funding of renal replacement therapy and the high profile of organ transplantation. Similarly, a study of healthcare decisions by elderly Medicare recipients found that financial resources were absent in their decision making (Hurwicz 1995).

Other studies have also reported that financial resources were the fourth major criterion in treatment decision models (Young 1980, Mathews and Hill 1990). This finding highlights the importance of other sociocultural issues in treatment choices raised by con-transplant patients and discussed in the beginning of this chapter. Medical studies of decision making for ESRD

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<sup>108</sup> It is a particularly American cultural trait to establish and utilize voluntary organizations (O’Connell 1983) to accomplish goals individuals could not ordinarily achieve alone. Throwing fund-raisers for transplants of all types is an example of a voluntary organization and is becoming increasingly popular. While there are no statistics to evaluate its popularity, clues of its increasing occurrence include: a) transplant social workers reported that they inform patients of this method of financing their transplantation, b) pamphlets educating patients of their treatment options recommend fund-raising campaigns (e.g., see UNOS 1997a), and c) the media (T.V., radio, newspapers) have aided in the fund-raising effort.

which found that religion plays an important role in treatment choices, confirm this conclusion (Holley, et al., 1996).

Theoretically, according to Waitzkin (1980), those in the poorest social positions should be disadvantaged in their access to transplantation. Striking for those concerned with structural issues that constrain choice and behavior, is that social position is not selected for or against in access to transplantation. Therefore, there are no structural constraints on individual decision making for the poorest or the wealthiest.

We must still account for the few patients who reported to be unable to afford a transplant. For these patients, and also for those who are trying to maintain a transplant, the cultural critique of medicine's proposition explains, in part, their decisions. That is, the structural organization of medicine, notably, the limited financial coverage for transplantation by Medicare and Medicaid, dissuades patients from seeking and/or maintaining the treatment for ESRD that offers a better quality and quantity of life -- kidney transplantation. In effect, patients with fewer resources are more likely to incur health problems associated with dialysis. Yet, if there were no limits to the coverage offered by Medicare and Medicaid, we may just as easily find the cultural critique of medicine's position problematic because patients also tend to incur health problems with transplantation, e.g., cancer. That either treatment for ESRD incurs health problems mitigates the argument by proponents of the cultural critique of medicine.

In this chapter we have examined how patients make decisions for treatment of ESRD. We have seen that patients' own decisions about treatment play a role, albeit relatively small, in their access to transplantation. Patients' decisions, in addition to the inadvertent or intentional subtle influences of healthcare professionals, ultimately effect the number and ethnic composition of people who are listed for a kidney transplant. The next chapter continues to

examine patients' treatment decisions, notably, decisions about changing treatment, and turning down offers of kidneys from cadaver and living (related) donors.

## **CHAPTER 8: ADDITIONAL TREATMENT DECISIONS**

We have seen in the previous chapter that patients have various cultural, social, and economic reasons for choosing to remain on dialysis or to seek a transplant. This chapter continues to examine patients' decisions about their treatment by deconstructing the sociocultural values and beliefs informing them. It also examines how some formal features of the healthcare system, e.g., policies and organization of health care, affect patients' decisions. Specifically, three additional decisions that may influence their access to transplantation are discussed: 1) the decision to change one's treatment modality, 2) the decision to turn down an offered cadaver donor kidney, and 3) the decision to turn down an offered living (related) donor kidney and/or the decision to not ask for a LRD kidney.

### **STABILITY OF DECISIONS OVER TIME**

Patients were interviewed over a six-month period to track the stability of their treatment decisions every three months. Identifying why patients change their treatment decisions, and determining the frequency of this change in decisions are important for assessing their understanding and thus choice of ESRD treatment modalities. Here we examine patients' reasons for deciding to change their treatment modality and data on the rate of this change (see Table 8.1).

**Table 8.1      Number of patients who changed treatment decisions by gender in the past and during the study period**

Gender	Changed Mind In Past			Changed Mind During Study		Total
	Pro-Con	Con-Pro	Pro-Con-Pro	Pro-Con	Con-Pro	
Male	6	0	1	0	3	10
Female	6	2	2	2	4	16
Total	12	2	3	2	7	26



A total of 9 patients (11.4%) changed their minds over the course of the study and 17 (21.5%) changed their minds prior to the study.<sup>109</sup> Because there is little data on treatment changes from other studies with which to compare, it is difficult to say whether 11% constitutes a large or small percentage of change for this population. The percent of patients who changed treatment modality reported here differs from other studies (see Chapter 4) for two possible reasons. First, the treatment decision was framed as between in-center hemodialysis and transplantation, while other studies accounted for submodalities. Second, patients' decision making was tracked over a six month period while other studies tracked patients over a longer period.

At the first follow-up interview, (T-2), which took place three months after the first interview (T-1), three (3.8%) of all patients interviewed had changed their minds. Two of them changed from not wanting a transplant to being interested in obtaining one. Only one changed from wanting to not wanting a transplant. At the second follow-up interview, (T-3) which took place at the six month mark, 6 of 75 (8.0%) patients interviewed had changed their minds. Of these, five changed in favor of getting a transplant and one decided against it. Most of the patients who changed their minds before and during this study were African American (11 of 17 vs. 7 of 9), and female (10 of 17 vs. 6 of 9).

There was a significant relationship between the direction in which patients changed their mind (only when combining those who changed before and during the study) and age ( $t=2.061$ ,  $p=.051$ ). Those who changed their mind from pro- to con-transplant tended to be older (52.7 years) than those who changed from con- to pro-transplant (44.2 years). There were no other

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<sup>109</sup> Two African American patients, one male and one female, had changed their minds both before and during the study.

significant relationships between sociodemographics and decisions to change one's mind either during or before and during the study, and the direction of the change.

Patients may be influenced by their healthcare providers to limit changes in treatment modalities, notably submodalities. For instance, during a predialysis education class, a new patient asked Joanne, a social worker, "If you try one [modality], can you switch?" to which Joanne responded, "Yes, but we *discourage* switching back and forth, because of all the surgeries." Another clinician-based factor that may influence patients' stability of decisions pertains to the timing of kidney patients' referral to nephrologists. A study of the relationship between referral patterns and dialysis modalities found that patients referred early tend to start on PD while patients referred late tend to start on HD in an emergency (Lameire, et al., 1997). In addition, Lameire and colleagues (1997) found that almost no changes were made in dialysis modality among late referred patients unlike those referred early. Patients who changed their minds during this dissertation study were evenly divided in the timing of their referral as sudden or progressive.

The direction of patients' change in treatment modality was primarily in favor of obtaining a transplant. There was also an increased rate of change in decisions toward the end of this six-month period. These trends may be due to increased discussions about treatment options by patients' nurses, technicians, or physicians (patients were likely to have met with their nephrologists twice during the study period). This is likely to have played a role in motivating patients to change their minds since patients reported to be influenced by family and care providers. It is unlikely that the Hawthorne Effect played a role in changing patients' decisions because the investigator did not advocate one treatment more than another during the interviews. Yet the increased number of discussions about patients' treatment options during the study period

may have generated additional thought about their health and future. Now let us examine the reasons for patients' treatment changes.

### **Shifting from Con-Transplant to Pro-Transplant**

Patients' decision to change from remaining on dialysis to seeking a kidney transplant is largely based on their perception of declining health and the desire to improve their lifestyle. Since dialysis presents a condition of lowered immunosuppression, many patients are more susceptible to infections. For instance, Andrew noted that he changed his mind because he was having problems getting infections on dialysis. Another patient, Louise, similarly explained that after ten years of dialysis, she had changed her mind just prior to study participation to seek a transplant because dialysis was adversely affecting her body. The ultimate factor that influenced her to seek a transplant was when her teeth began falling out from the adverse effects of toxins building up in her body from dialysis. Louise attributed her original long-term resistance to transplantation to having listened to other patients' worries and anxieties over the negative effects of transplantation.

Other patients (n=6) had become "tired of going to dialysis" and sought improvements in their lifestyle that a transplant promised. For Gloria, this meant "be[ing] able to get around more, walk to the store." For two men, (Roland, Marshall) this meant greater freedom and financial stability by returning to work. Both men contended that they were used to a lifestyle that Social Security Income could not support, e.g., paying mortgage bills. Roland explained in greater detail the reasons for his desire to seek a transplant: "I don't like getting money once a month. I'm not used to that. It's mentally impossible to adjust to it." He continued:

"I want more freedom. I'd like to have more of my life back. That would free me up some. I want to go back to work. Now that I'm single (he paused), I want to live a little bit now... this is so confining. If I miss a day, I'm getting out of breath. A lot of little things I'm thinking about have prompted me to get a transplant." His decision was reinforced by the idea of being able to "cut down on this [dialysis] three times a week and the freedom" that a

transplantation entails. A transplant would give him “more freedom, free me up from having to be put on this three times a week... always make allowances for these three days.”

The concern about declining health as a reason con-transplant patients presented for changing their mind to seek a transplant corresponds with the reasons why pro-transplant patients desired a transplant. Other studies of treatment decision making similarly show that patients’ assessments of the gravity of illness is a primary consideration in decisions to seek care from healthcare professionals (Hurwicz 1995; Young and Garro 1981; Mathews and Hill 1990).

### **Shifting from Pro-Transplant to Con-Transplant**

One of the two female patients who changed her mind in favor of remaining on dialysis during the study attributed her decision to a spiritual experience. After completing the transplant evaluation process, Tammy (who practiced Metaphysics) was meditating one day and experienced a flash vision of the transplant operation happening. In her vision, the operation went too quickly and it did not work out. After this experience, Tammy called the transplant secretary to remove herself from the transplant list. Another patient, Annette, realized that the costs of transplantation were too high for her and remarked, “you have to wait so long, anyhow.”

Prior to their participation in this study, twelve patients had previously sought a kidney transplant as treatment for ESRD but had changed their minds in favor of remaining on dialysis. Ten of these twelve patients had begun the transplant evaluation process, and five of these patients had even completed the evaluation process but then removed themselves from the waiting list. Several themes emerged in these patients’ reasons for changing their mind against seeking a transplant.

Some of these patients (n=5) were convinced by their nephrologist or social worker to seek a transplant. However, while these patients set up their evaluation appointments, they

remained uncertain about transplantation and stopped their involvement in the evaluation process. For instance, patients commented:

Barbara: "Joanne [social worker] was talking to me. I was having such a hard time on dialysis. [I didn't go to the appointment because] I didn't feel like going anyway, I just listened to Joanne. She had people talk to me on PD."

Michael: "Basically, the doctor talked me into it and everyone else -- friends wanted to sell their kidney [but during the evaluations I] "even had in mind I probably wouldn't get a transplant."

Two patients originally sought a transplant when they initiated dialysis because they felt forced into it since they were told by their physicians that they were going to die in a few months without one. Both men were initially minimally informed about dialysis which led them to seek a transplant. These patients articulated how this happened:

Lewis: "Then, I was scared, I had no knowledge about dialysis, I thought with a transplant I would live."

Malcolm: "[When I started dialysis,] people [were] throwing stuff at you, I don't know why I said OK. I was angry. I didn't want to be in this chair. I didn't think I was going to. I didn't know much about it. People came up with different view points."

Evidently, some patients began the evaluation process at their clinicians' persistence, and partly because of their confusion about their new ESRD condition. The following are reasons why patients changed their mind and discontinued the evaluation process.

While meeting with transplant professionals for transplant evaluation, four African American patients came to realize the clinical complexity of transplantation: medicines, surgery, and ongoing medical appointments. For instance, midway through her evaluations Pauline changed her mind because "getting a transplant involved so much" and she "didn't want surgery no more." Another woman, Virginia, stated: "when they started to talk about all the medications... I'm already on a lot of medicines. I've never been a pill popper."

The concern about taking additional medications was especially salient since many patients had previously been on steroids and wished to avoid retaking them with a transplant, as expressed by another patient, Janet: "I wanted one [a transplant] in the beginning then I was

hesitant because of steroids.” In addition, patients observed the adverse effects of transplantation among other dialysis patients. One patient, Dorothy, “heard from other people, several had more complications now than before from accidents. That discouraged me a little bit.” Further, several patients specified that they did not like the idea of having to visit the hospital routinely because, as Dorothy noted, “I already come here three times a week.” Patients who voiced this concern seemed not to take into consideration that they would no longer be attending the dialysis unit following transplantation.

Patients also changed their minds because they realized that they could remain on dialysis and maintain other aspects of their lifestyle. For instance, two patients noted that they could still work while on dialysis:

Virginia: “The only reason I would consider transplantation is to go back to work. But now my doctor said I could go back to work... I always wanted to go back to work, I was just kind of skeptical if I was able to because of lifting.”

Lewis: “But once I found out I can be on dialysis and it would preserve my life for 5 to 10 to 15 years... I met a guy on dialysis who’s been on for 23 years... So I’ll take my chances... I see some people where they are on dialysis and they can’t do nothing but I can work everyday and plus I drive.”

Other patients felt overwhelmed at first with the prospect of transplantation and required time to psychologically prepare themselves for it. For instance, Juliet said that one reason she did not attend her appointment at the transplant center is because “They don’t let you get used to dialysis” and she felt that the idea of transplantation was “too overwhelming” for her at that time. In addition, Juliet did not attend her appointments because she did not like the double-bind she was in. On the one hand, she disliked that her appointments were scheduled on non-dialysis days because that meant “I’m here 5 days a week” and she lived about an hour’s drive away. On the other hand, since she did not attend these, the transplant secretary threatened her by saying “if you keep this up, you’re not going to be considered a candidate.” In response to this tension Juliet said “forget it.”

### **Influences on Decision Stability**

To gauge how steadfast all patients' decisions were, patients were asked two questions:

1) Would your view of transplantation change if your health was worse? and 2) Would your view of transplantation change if your health was better? A total of 47 (59.5%) patients stated that they would change their mind about transplantation if their health changed in general (See Table 8.2).

**Table 8.2 Patients who would change their view of transplantation depending on changes in their health status (n=79)<sup>1</sup>**

	Health Worse	Health Better	Total
Want a Transplant Even More	20 (25.3%)	6 (7.6%)	26 (32.9%)
Want a Transplant Even Less	12 (15.2%)	3 (3.8%)	15 (19.0%)
Not Specified	3 (3.8%)	3 (3.8%)	6 (7.6%)
Total	35 (44.3%)	12 (15.2%)	47 (59.5%)

1. Six patients replied "I don't know" and were not included in analyses.

Thirty-five (44.3%) patients indicated that they would change their view of transplantation if their health was worse; 6 (7.6%) patients responded "don't know." Of the thirty-five patients, 20 (57.1%) would want a transplant even more, while 12 (34.3%) would want a transplant even less, and 3 patients did not specify how they would change. The basis for wanting a transplant even more in the case of worse health was because dialysis would have proven to be ineffective in maintaining health. As two patients noted:

Roland: "It's an even bigger motivating factor if it [my health] was worse -- I'd be feeling a lot worse."

Marshall: "I probably would because it would be the last resort for me. Right now I'm comfortable with the way I am now. I can't say I would [get a transplant] but it would influence me to do it."

On the other hand, patients said that they would be less inclined to seek a transplant if their health was worse because of the understanding that they would no longer be medically eligible for it and/or there would be less likelihood of a successful outcome. Patients noted:

Tammy: "If I had some serious illness problems, yes. I don't think I would be interested. It wouldn't be sensible."

Joshua: “[I’d] probably say to hell with it [because I’d be] feeling down in the dumps. I heard they don’t give kidneys to people feeling like that. Why waste a kidney if you’re feeling bad all the time. You’re probably going to die, so why waste it.”

Bruce: “I wouldn’t take it -- it’s a waste of time. If I’m going to die, why worry about it.”

Twelve (15.2%) patients indicated that they would change their view of transplantation if their health was better; 6 (7.6%) patients responded “don’t know.” Of the twelve patients, 6 (7.6%) indicated that they would want a transplant even more, while 3 (3.8%) would want a transplant even less, and 3 patients did not specify how they would change. Patients indicated that if their health was better, then they would be less interested in obtaining a transplant and in less of a hurry. Consider these statements:

Fatima: “I probably still want it but it’s not a rush, like I have to get it right away.”

Samuel: “If better, I still have my mind on getting a transplant but not worry as much.”

Raymond: “If [I was doing] really good, I may not want it.”

On the other hand, patients indicated that they would be even more inclined to seek a transplant in the case of better health because their body would be better able to undergo the surgery. One patient commented that he would want to “Hurry it up so I could get it,” and another patient, Naomi, stated that if she were feeling better, then she would “be able to take it better.” Comparing the treatment status of patients with regard to these two variables we find one significant relationship. Significantly more con-transplant patients than pro-transplant patients would reconsider in favor of getting a transplant even more if their health was worse ( $X^2 = 10.013$ ,  $p = .007$ ,  $n = 70$ ).<sup>110</sup> The responses to these two questions suggest that patients’ level of motivation to seek a transplant is related to their perception of health.

As these data show, patients are always faced with the choice of changing their treatment decisions because of the nature of their treatment environment. As we will examine in the next

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<sup>110</sup> Six patients who responded “don’t know” and three patients who responded “yes” but did not specify how their view would change, were excluded from this chi-square test.



chapter, nephrologists are required by law to annually and semiannually discuss the transplant option with patients. Doing so continuously reminds patients of their capacity to change their mind. In addition, in the dialysis environment patients witness and hear the stories of the treatment changes made by other patients. In such an environment, patients may come to view treatment change as an accepted part of managing their ESRD.

### TURN DOWNS AND REMOVAL/WITHDRAWAL FROM THE WAITING LIST

When patients are offered a cadaver-donor kidney, they occasionally turn it down. While this patient-based decision is not uncommon, it does explain, in part and by default, who does not get access to kidney transplantation. This phenomenon and the reasons why some ESRD patients turn down offered kidneys have gone unaddressed in the transplant literature. Only UNOS (1992a:2233) has acknowledged that patients turn down kidney offers because they feel that the timing of the prospective transplantation in their lives is not right. To gain a broader perspective on this issue, transplant professionals (physicians, nurses, and social workers) were asked about the reasons patients provided for turning down kidneys in their experience. According to the AH head transplant surgeon, there are approximately 10 to 15 patients who turn down a kidney per year.

When transplant coordinators notify (via telephone call or page) potential recipients about an available kidney, the first question they ask patients is “Do you want to do this now?” For most patients, the telephone call comes as a shock since they never know when it is coming. The call can be made on days, nights, holidays, or weekends. If the call comes in the middle of the night, recounts Jennifer, a transplant coordinator, some patients said that “we just don’t feel like coming, can we do this tomorrow maybe?”

Some patients do not want the kidney because of things happening in their life at the time. For instance, transplant coordinators have had patients turn down a kidney because they were getting married or attending their mother's funeral the following day. Many patients refuse the kidney offer because they say that they are simply not ready. For instance, Kathy, a transplant coordinator, noted that some patients refused a kidney because they had to take care of sick loved ones. A transplant surgeon, Dr. Riley, interpreted such patients' state of mind to be "Like, the unexplained reasons why they won't get on an airplane at that particular moment at that particular day, tells them that this isn't the right thing for me to do." Transplant coordinators also ask patients how they are feeling physically. If patients have an acute illness or an infection, e.g., a temperature or a urinary tract infection, then they are clinically unable to go through the surgery.

Transplant professionals agreed that the main reason for turning down an offer was fear. Patients are afraid of going through a major surgery, the consequences of rejection, and dying. According to Brian, a social worker, patients turn down kidney offers because for them "it's like jumping off a cliff, an act of faith" and patients do not like the unknown aspect of it. This fear relates to the fear of losing control during surgery, as discussed in Chapter 7. Part of this fear is due to hearing about adverse effects of transplantation on other patients. A transplant coordinator reported that within a month after two patients died from a transplant at AH, a couple of patients called to remove themselves from the list. She related this occurrence to the fact that information about patients' deaths gets back to the dialysis unit so that patients become aware of it. Interestingly, both patients who called belonged to the same dialysis unit.

While many patients are fearful, those who turn down a kidney usually still desire a transplant but at a later date. Patients who make treatment decisions based on the clinical

outcomes of unsuccessful kidney recipients fail to place those outcomes into context of the statistical likelihood of them occurring. In addition, such patients contradictorily base their decisions on biomedical conditions which have all been founded on statistical analyses such as Cytomegalo Virus (CMV), age, and warm ischemia time.

Another reason three transplant and dialysis professionals believed that patients say they are not ready for a transplant is because patients have become stabilized on dialysis and are doing well but do not want to ‘rock the boat.’ As Dr. Olson noted, “you’re going to be trading a known entity for something that [is] unknown but has an immediate downside and can kill you.” This nephrologist related the tendency for patients to feel this way to the improvements of dialysis over the past decade.<sup>111</sup>

Another factor influencing patients to turn down offered kidneys is knowledge gained about the donor and the donor kidney. When transplant coordinators call patients about an available kidney, they may inform patients about the donor’s manner of death, age, sex, “race,” and kidney condition, e.g., “the donor is 35 years old, was a motor vehicle accident.” For instance, patients offered a borderline kidney from elderly donor may chose to decline it, as in the case of a 40 year old patient offered a borderline kidney from a donor who was in the range of 60 to 70 years old. In addition, transplant coordinators may inform patients of the warm ischemia time, that is, the amount of time that has passed since the donor kidney has been harvested. Sometimes patients turn down the kidney offer if they personally think the warm ischemia time has been too long because the longer the kidney has been out of the donor’s body, the lower likelihood of it being physically accepted by the recipient. Patients can also stipulate

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<sup>111</sup> This change was discussed at greater length toward the end of Chapter 5.

the type of match they are willing to accept. For example, patients may tell the transplant center to inform them only when there is a perfectly (6 antigen) matched kidney available.

The extent of information provided to patients depends on the transplant surgeon's progress in "harvesting" the kidney. Some transplant coordinators will provide more information than the fact of an available kidney if patients specifically ask for it. The reason for not offering automatically more information about the donor's kidney is because transplant coordinators must usually notify several potential recipients within a limited time span. In addition, transplant professionals must abide by UNOS law, to maintain confidentiality of the donor's identity. Dr. Alland helps his patients make informed transplant decisions by advising them to ask the transplant coordinator about how good the kidney being offered is when they are called. He explained why:

"I tell them that you may not fully understand how they respond to you, what they say in response. But the fact that you've asked the question will put them on notice as needing to go beyond the fact that we have a kidney for you... we have limits in terms of acceptability of transplantable organs, but those limits are broad... And you are entitled to know in general terms what that kidney is because if in fact it's not such a great kidney and it doesn't work for you for any sustained period of time, remember that you go back to the bottom of the list."

In deciding whether to accept a cadaver-donor kidney offer, some patients assess the quality of the kidney from their perspective. This assessment entails determining if it is a marginal kidney. The older the kidney and the more illnesses that afflicted the donor, the less functional it will be thereby rendering it marginal or more risky. As Dr. Alland put it, "kidneys are like used cars and some of them are very good and some of them are absolute clunkers." Patients must decide, for instance, whether to accept a kidney that is CMV positive or is antibody positive for hepatitis C. Patients who have already been exposed to CMV are considered 'positive' while those who have not been exposed to it are 'negative.' Since the virus can be passed through the kidney, potential recipients who test negative to CMV may turn down a donor

kidney which is positive because the transmission of the virus is a serious medical risk for transplant patients in an already immunocompromised condition. Normally this viral infection does not cause any problems unless the immune system is suppressed. While transplant coordinators do not always reveal the CMV status (unless a patient asks for it) because there are ways of treating it, transplant professionals feel that it would be medically unethical to give a patient a kidney with a viral liver disease without telling the patient first or asking permission, as Dr. Riley noted.

The AH transplant center makes a distinction between legitimate and illegitimate reasons for turning down kidney offers. Legitimate reasons for turning down kidneys include the increased risk (due to the donor's infection or increased age), or because the patient is sick, or is in the midst of significant life events. In contrast, illegitimate reasons for turning down kidneys include not feeling ready or fear. A comment by Dr. Gilmore on this issue provides perspective on why fear is seen as a less valid reason for turning down a kidney:

"I think somebody who really really wants a kidney is going to take it whether it's a holiday or if it happens to inconvenience them a lot. That's my understanding of how precious the resources [are,] most patients aren't going to turn down the kidney."

Both the reasons patients provide for turning down a kidney and the number of times they turn down a kidney can count against them in obtaining a transplant. All patients at AH are allowed to turn down two cadaver-donor kidney offers for any reason. After the second turn-down, the transplant surgeon sends a letter to the patient and their nephrologist advising them that any further turn downs will result in removal from the list. This letter serves as a way to open the door to further communication about personal concerns the patient may be having. The basis for this procedure is to conserve transplant center resources. Transplant coordinators must take the time to keep track of patients on the list and notify them (often at midnight) of an

available kidney. In addition, it costs the transplant center approximately \$281 per month per patient on the waiting list for the antibody screening. Thus, if patients do not actually want a transplant, removing themselves from the list could thus save the transplant center time and money.

Even less common than turning down kidneys is the practice of removing patients from the transplant waiting list. Most patients are removed from the transplant list because they have died (UNOS 1998h). Others are removed because they have moved to another city or to another hospital for insurance reasons, or they transferred to another waiting list. Still others are removed because they no longer want a transplant or engage in noncompliant behavior.

Data on turning down a kidney or removing oneself from the transplant waiting list were collected from patients in the study sample.<sup>112</sup> Three patients reported having turned down an offer of a kidney and removed themselves from the waiting list prior to study participation. All of these patients were male and had also changed their minds prior to the study to no longer seek a transplant. One European American patient, Edward, turned down two kidney offers because he did not like the quality of the antigen match and the donor's age; his surgeon removed him from the list shortly thereafter. The following are the other two patients' narratives about how turning down kidneys resulted in their removal from the waiting list.

Malcolm, a 50 year-old African American man, explained that in addition to concerns about his health, his perception of a power struggle with the transplant surgeon, Dr. Benton motivated him to decline the kidney offer. Malcolm recalled that when he was called about the available kidney, "I didn't think it was the right timing. [There were] little things wrong with my health. I wanted to be sure [that I was healed]." He believed he needed to heal his broken leg first before getting a transplant because Prednisone retards the healing process. The clinicians "made remarks about me being scared. I've been through a war, I'm not scared, but scared of foolishness. I was ticked off because of that remark. They told me it's nothing to worry about, but I see people dying around me, it must be something to worry about." When Dr. Benton spoke to Malcolm about taking the available kidney, Malcolm was resistant because he had been "moving at his pace and not Dr. Benton's pace." Malcolm reported that Dr. Benton had told him, "If you don't take this kidney, I will take you off the list," and thought aloud, should I be begging,

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<sup>112</sup> Due to confidentiality reasons at the transplant center, I was unable to contact patients not included in this study who had turned down a kidney or removed themselves from the transplant waiting list.

“oh, don’t take me off the list...!” But instead he affirmed that “This is my body.” He said that being removed from the list seemed like a “threat” to him.

Lewis, a 42 year-old African American man, recounted how he had been called for a transplant twice and declined both times because “I felt I could live on dialysis.” “He [the nephrologist] had been upset about [me] turning the kidney down.” The first time Lewis was called for a transplant it was 1 or 2 pm and he was at work, working on an air conditioning unit. He noted that the call “had caught me off guard... My pager went off. It actually scared me. They told me to call the hospital but I didn’t.” His wife had paged him and told him that he needed to call the hospital within 45 minutes. But he did not call the hospital because of “fear.” Lewis explained his fear: “I just couldn’t see. I hadn’t had time to pray. If I am going to have a transplant, or other surgeries, I want to at least ask my God to forgive my sins.” He continued, “I’m not worried about surgery if I had time to prepare. If I had time to tell my wife, daughter how I feel about them in case I died, but I’m at work, I have to get to the hospital in 45 minutes, [there wasn’t] time to tell nobody I love them and that means a lot to me in case it doesn’t work.” Lewis also framed his concern in terms of being the male provider of his family: “all my family are women and dialysis is working for me. I can still do things... [It] makes me feel like I’m responsible for my sisters, daughters, wife, mother. I support most of them. I’m in a good position -- I’m an engineer. With me off work, money is not going to be there.” The second time he was called for a transplant, Lewis was in the hospital to clear an infection in his graft. He was required to turn down this offer because of the infection “but I would have [taken the kidney] because I was sick. As sick as I was (I lost 27 pounds), I was really considering it. I had a temperature of 104.” I asked how he decided to go off the list after being on it for 3 years: “I don’t think I decided.” Dr. Benton wrote him a letter stating that Lewis could only turn down one kidney, and if he turns it down again, Dr. Benton would “automatically take me off the list.”

Turning down kidneys and self-removal from the transplant waiting list may explain in part why groups of people such as minorities, e.g., African Americans, and women wait for longer periods of time for a kidney transplant. In the US, patients refused a kidney transplant offer 152 times during 1997, and a total of 1,295 times between 1990 and 1997 (UNOS 1998h). Of all the kidneys not used at AH between 7/1/95 and 6/30/96 (n=34), 4.4% of them were due to patient refusal of the offered kidney (UNOS 1997e). During this same period there were 353 patients on the AH waiting list, a total of 73 kidneys were offered.

Since so few patients in this study had turned down kidneys, statistical analysis of the relationships between ethnicity or gender and turn down decisions is not possible. While UNOS does not track the sociodemographic profile of patients who refuse kidney offers, discussions with transplant professionals revealed some useful information on this subject.

According to Dr. Benton, experience at the AH transplant center and nationally shows that African Americans tend to turn down kidneys more often than European Americans. When

transplant coordinators tell patients that they finally have a donor after waiting two to five years on the waiting list, Dr. Benton finds that “more often that we will have a black patient tell us, ‘Well, I’m doing OK, I don’t think I want the transplant anymore’ whereas white patients for example, will jump out, almost always for the transplant.” Dr. Benton speculated that the root of this difference in ethnic groups in turning down kidneys pertains to their experiences on dialysis. Specifically, he proposed that:

“There may be more communication in the sense of a community among the black people on dialysis and they may share with each other, each other’s experience more, and so when I think somebody has an adverse effect, like a transplant death or a failure, that result may make the rounds so to speak more in the black community than in the white community. And that’s a perception on my part, it may not be completely false, but it’s a perception that I have. Because we’ll often have black patients who come in and say, ‘I know this guy, and this guy didn’t do well, and so forth and so on.’”

Dr. Benton’s comments implicitly touched upon two factors influencing the different turn down rates by ethnic background: community and oral culture. African American patients seem to experience the dialysis unit as a community environment. As a community, patients openly talk, joke, share stories about others with one another, and offer words of support. As Erika, a dialysis social worker pointed out, whenever she enters the dialysis unit at NDC 1, which is primarily African American, she always says hello to the whole room of patients who greet her in return. She explained that if she were to not openly greet them, African American patients would feel insulted since they would not feel acknowledged. She contrasted this practice to her interactions with primarily European American patients at another dialysis center which were characterized by more one-on-one communication. While European American patients tend to prefer written material for communication, African American patients tend to prefer oral communication. Erika learned that she is most effective in helping patients cope with their finances, housing, transportation issues by handing European American patients written



pamphlets to read on their own and by discussing these issues directly with African American patients.

Turning down kidneys may be a cultural practice among other groups of people. A transplant coordinator from a Southwestern transplant center informed the investigator over the Internet that the one Native American patient (out of a total of four) turned down a kidney because he was afraid of a dead person's kidney inside of him. This explanation makes sense within many Native American, notably, Navajo, understandings about death and contact with dead organisms. Specifically, contact with the dead and the ghost connected to it is especially dangerous because mishandling a dead body is believed to cause sickness (Sandner 1991:102). The idea of accepting another person's kidney may be particularly scary for Navajos because of the cultural practice of quickly burying dead people and letting them get incorporated back into nature (Sandner 1991).

As we have seen here, patients may turn down offered cadaveric kidneys for various reasons, some for clinical and some for personal reasons. While these data can begin to build our limited knowledge of this practice, it is clear that such a patient-motivated practice of turning down kidneys results in patients not obtaining transplants. In the next section we will examine why patients even turn down offers of living-donor kidneys.

#### LIVING (RELATED) DONORS (LRD) VERSUS CADAVER DONORS (CAD)

According to the medical decision-making literature, patients generally have more treatment options than they perceive to be available to them. Patients' perceptions of available treatment options are likely to be limited by sociocultural and socioeconomic factors. Dialysis

patients interested in a transplant have a choice of two donor sources, cadaver donors and living (related) donors.

Given a choice, we might assume that patients would select a LRD because of its many advantages. For instance, patients can get a kidney transplant much quicker with a LRD than if they waited for a CAD because the operation can be scheduled as soon as both parties have completed their work up process, which takes on average two to three months for the recipient and two months for the donor. Waiting only two to three months for a LRD transplant is much less than waiting three to five years for a CAD transplant. In addition, medically, LRD kidneys have better graft and patient survival rates than CAD kidneys because of the closer genetic match between family members than between strangers.

However, there are also risks to the LRD. For example, donors: a) may be harmed from the operation, b) tend to have longer recovery periods than do recipients, and c) are out of work for about six weeks following the surgery thus presenting a financial challenge. While transplant surgeons assert that there has never been a case of a donor death at any transplant center, LRDs are still relatively new in practice such that longitudinal data spans only about 30 years.

In this study, many patients chose to limit their donor option by refusing to accept an offer of a LRD kidney and even refusing to ask a family member to donate. This patient preference can be seen as one factor hindering (quicker) access to transplantation. Patients' attitudes about LRD were elicited to discern whether there were sociocultural factors influencing their decisions. In addition, it was hypothesized that there may be differences in patients' willingness to accept and to ask for a LRD by ethnicity, gender, age, and relationship to the donor.

Among the sample, there was an overriding sense that although living donors have an extra kidney to spare, patients expressed reluctance to accept it because they feared it would harm the donor. The general thinking can be broken down into several assumptions about 'kidney donation' and 'asking for a kidney.' These assumptions are expressed along the lines of: "I would like a kidney transplant, but (1) I do not want to accept or ask for a LRD because of the risks to the donor (or the donor's family). (2) Because of these risks, I would rather deal with my problem alone, (3) unless an emergency comes up and I really need to get a kidney, then I will ask someone to donate or accept a LRD offer. But even if no one offers to donate, I could not ask anyone to donate because (4) asking people is difficult to do, and (5) it makes them feel obligated to donate, and I don't want to put people in that position since organ donation should be voluntary." Patients expressed at least one of these assumptions, and occasionally made links between them.

Patients' attitudes about accepting an offer of a LRD and about asking a family member to donate largely overlap. Most of these overlapping data are presented in the section on declining a LRD offer to prevent repetition and facilitate flow of the discussion. We begin by discussing the first three assumptions since they all pertain to refusing a LRD offer. The last two assumptions will be discussed later on because they are issues raised by patients about the prospect of asking someone to donate.

### **Refusing LRD Offers**

While 81.0% (n=64) of the entire sample had been offered a LRD kidney, only 39.1% (n=25) of these patients would accept it on the basis that the donor's kidney was a match (See Table 8.3). Specifically, of the pro-transplant patients who were offered a LRD (n=42), only half (n=23) would definitely accept it, and 4 might later accept it. Of the pro-transplant patients who

were not offered a LRD, most (n=5 of 7) would definitely accept it, and 1 might later accept it. Of the con-transplant patients who were offered a LRD (n=22), only 2 would accept it now, and 1 might later on. Clearly, significantly more pro-transplant patients than con-transplant patients would accept a LRD kidney ( $X^2=15.139$ ,  $p<.001$ , Fisher's Exact Test). It is remarkable that patients who wanted a transplant have turned down a LRD offer because doing so diminishes their chances of getting what they want: a transplant. The large number of con-transplant patients who declined a LRD offer is not surprising given that these patients did not want a transplant anyway.

**Table 8.3      Number and percent of patients offered and willing to accept a LRD kidney transplant**

	Patients offered LRD	Of those offered, # who would accept	Accept LRD, regardless of offer
Pro-Transplant	42 (65.6%)	23 (54.8%)	28 (43.8%)
Con-Transplant	22 (34.4%)	2 (9.1%)	4 (18.2%)
Total	64 (39.1%)	25 (39.1%)	32 (40.5%)

Among pro-transplant patients who were offered a LRD, there were no significant relationships between willingness to accept a LRD and ethnicity, education, income, age, and religion. However, the relationship between willingness to accept a LRD kidney and religion was significant among the entire sample who was offered one ( $X^2=12.623$ ,  $p=.013$ ). Those who were not willing to accept a LRD kidney offer were primarily of Protestant denominations (88.2%), while those who were willing to accept a LRD kidney offer were Protestant (52%), Catholic (36%) and other (12%). All five patients who indicated that they later might accept a LRD kidney offer were of Protestant denominations. However, this relationship was not significant specifically among either pro-transplant or con-transplant patients.

There was also a significant relationship between willingness to accept a LRD kidney among all patients who were offered one (n=64) and ethnicity ( $X^2=8.405$ ,  $p=.015$ ). While twelve

of African Americans and European Americans equally indicated their willingness to accept a LRD kidney, those who were less willing to accept a LRD kidney offer were significantly more likely to be African American. Specifically, 63.6% of African Americans (n=28) and 27.8% of European Americans were not willing to accept a LRD kidney offer. Four of five patients who indicated that they later might accept a LRD kidney offer were African Americans. This relationship, however, was not significant specifically among either pro-transplant or con-transplant patients.

### Risks to the donor

Patients shared similar reasons for refusing their LRD kidney offers and their unwillingness to ask for a LRD kidney. By far the most common reason for not accepting or asking for a LRD kidney was because of the risks it imposes on the donor. Patients' anxieties about risks to the donor were expressed in several ways: a) donating a kidney can harm a donor during and immediately after surgery, b) donating a kidney may eventually harm a donor by resulting in the need for a kidney themselves later on, and c) donating a kidney can shorten the life of the donor. This last concern was most often raised when young adult children were potential donors. The following discussion explores in greater detail each of these concerns about risks to the potential donor.

### *Immediate harm to donor*

Eleven patients expressed fears that family members who donate would incur serious risks, including the harm of surgery and the pain of recovery. Most of these patients were pro-transplant (n=8), male (n=7), and African American (n=7). Patients clearly drew upon their recollection of meetings with transplant surgeons (and perhaps discussions with other patients about LRD) as the basis of their knowledge about risks to donors. Pervasive in patients'

statements was their emotional discomfort with the suffering that donors would have to endure particularly since donors would otherwise not need surgery. Consider the following statements:

Warren: "I'm not going to endanger somebody else's life to save mine."

Mindy was reluctant about accepting her father's offer "because I heard it's really hard for the donor (they break the ribs [to get to the kidney]), the donor's in the hospital longer than the recipient, and I don't want him to go through that."

Mark: "I don't want her to do it, get cut on... She's all right now and I want her to stay like that. I don't want anything to happen."

Eight patients framed their fear of these risks to the donor in terms of feeling "guilty" if they accepted the LRD kidney and it rejected or the donor became sick following the donation. Most of these patients were pro-transplant (n=5), female (n=5), European American (n=4), and African American (n=3). In other words, patients would feel at fault for the rest of their lives if the donor was harmed. Consider the following statements:

Mindy: "If something happened to my father, if it didn't take, [I'd] have to go back on dialysis... [I would] never forgive myself if something happens to my father."

Chantal expressed worry about her husband and children donating, respectively: "What if he gets sick. What if something happened to his kidneys, I would be devastated... [I'd feel] guilty probably because of the thing they had to go through if anything happened. It would be in the back of my mind all the time."

Cecelia: "If anything happened to their kidney, I'd feel I was to blame for this."

### *Donor might need a kidney (or dialysis) later*

Transplant surgeons routinely inform patients who are seeking a transplant that living donors can live with only one kidney. However, patients' comments reflect skepticism of the safety of living donation. Five patients (three European Americans, three females, and three con-transplant patients), for instance, voiced their uncertainty about the safety of living with one kidney:

Malcolm: "I know a person can survive off of one kidney, but the rationale don't make sense. I got two and I'm not as good as one kidney."

Barbara: "If they had two kidneys they could live longer. If they had only one kidney, they have to be so careful. They have more chances with two than one."

Dennis: "I have to talk to her doctor, what would be her health down the road, is that extra kidney going to help her along better?"

These comments may reflect a lack of understanding that renal failure afflicts both kidneys rather than selectively afflicting one. Transplant surgeons recommend that LRDs keep their remaining kidney healthy by taking preventive measures including maintaining low blood pressure, annual medical checkups, and avoiding traumas like car accidents. Somehow it appears that patients interpreted the surgeon's suggestion in an exaggerated manner because they expressed the belief that donors risk requiring a kidney or dialysis later in their life. Perhaps the basis for their protective stance toward the donor was their understanding of heredity, for many of their own family members have ESRD. Six African American patients therefore did not want to accept a LRD kidney offer because they did not want to incur harm to a loved one. Four of these patients were female and con-transplant. The following statements exemplify these concerns:

Donna: "Everyone has sickle cell anemia or the trait and plus I wouldn't want to take a kidney from them, and they would end up with one kidney and might end up on this. If I can avoid it, I wouldn't take their kidney. Who's to say what would happen?"

Talmadge: "I just wouldn't [ask]. I believe it's too big of a sacrifice. [EG: why is it a sacrifice?] [because someone would] donate a kidney and then one day, [what if] what they had went bad?"

Marshall: "They might go through the same thing and they'd only have one kidney. Something might happen to their one kidney."

The next set of statements reflect another facet of patients' concern about the risk to the donor. Four patients refused to accept a LRD kidney offer because they wanted the 'spare kidney' to go to other family members who might need it later in their lives. Of these patients, three were female and three were African American, and two were pro-transplant patients. This was most notable among parents who declined their adult children's offers because they preferred that their children donate a kidney to the patients' grandchildren who may need a

kidney in the future. Their reasoning is 'future-oriented' (Zborowski 1969) since patients implicitly perceived the donor's kidney as a 'spare' or 'reserve' part that can be used in the future. Fox and Swazey (1992) used the term 'spare part' in Spare Parts to refer to organ transplantation in general. But they never addressed this meaning of 'spare part' within the context of living donation. Patients' statements indicating this view include the following:

Juliet: "My fear is that I'm going to get a family kidney and then someone in the family is going to need it after."

June: "I didn't ask him because he was family, if one of his kids needs a kidney, I wouldn't want to jeopardize it... [Accepting his kidney is like] taking something away from his family. I don't want him to go to the hospital and get cut on... If his kids got sick [with kidney disease] what is he going to do? I feel I'd deprive the children. I never know what would happen."

Andrew: "I wouldn't want to impose it on my kids because they might need a kidney... I wouldn't send her through that way. I would never ask them. You got to take time off from a job. My daughter has kids, and kids need time with their parents. Then if something happened later on and they need a kidney or their kids needed it. If it runs in the family... [we're all] diabetics."

### *Shortened lives*

Ten patients (5 pro- and 5 con-transplant) believed that donors were open to another risk: shortening their lives. The majority of these patients were male (n=7) and African American (n=7). The average age of this group of patients was 50 years of age. Again, adult children were the focus of patients' concerns. Patients emphasized that their children were too young to go through such a trauma to their body. As previously noted, patients implicitly conveyed that hereditary diseases in the family may afflict their children later, so having them donate now might cause them even greater harm when the disease is eventually diagnosed. In addition, older patients claimed to have already lived a long life and that it would not be worthwhile to expect their children to donate.

Barbara: "If I took a kidney from my kids I wouldn't feel good shortening their lives... They have a long life ahead of them. I have high blood pressure. I feel one of them will end up with my problem." She asserted that accepting a kidney from her kids was "even worse" because they are young and "I want them to have a life [like I did] before I got sick. They might lose a kidney [if they donated]."

Henry: "My children are just beginning [their lives.] They don't need to start off with a disability."



Roger: “[I want my daughter to] keep her own kidney [because] she’s young [and] I’m old- 60- I don’t need a kidney... I’m an old man, it wouldn’t be right.”

Clearly, as patients articulated in the above section on risks to donors, age and the relationship of the potential donor to the patient strongly factored into patients’ decisions about refusing to accept a LRD kidney offer. Since the majority of all patients in the sample (and most with ESRD in general) were of upper middle age (e.g., 48 years), it was unlikely that their own parents or other relatives of an older generation would be medically suitable to donate a kidney. Thus, the fewest offers to donate were made by the generation older than the patient. Most of all the donor offers were made by contemporaries, including siblings, cousins, and friends. The second largest group of donor offers was made by a younger generation, including children, nieces, and young cousins. See Table 8.4.

**Table 8.4 Number of LRD kidney offers by generation of donor in relation to the patient by treatment decision**

Relationship	Pro-Transplant (n=41) <sup>1</sup>	Con-Transplant (n=22)	Total (n=63)
Older	34 (21.9%)	3 (5.8%)	37 (17.9%)
Contemporary	91 (58.7%)	22 (42.3%)	113 (54.6%)
Younger	30 (19.4%)	27 (51.9%)	57 (27.5%)
Total	155 (74.9%)	52 (25.1%)	207

1. One patient was excluded from analysis because the donors were of uncertain number.

Among all pro-transplant patients who were offered a LRD kidney (n=42), there was a significant relationship between the gender of the patient and the generational background (e.g., parent’s generation, contemporaries, children’s generation) of the potential donor ( $X^2=17.958$ ,  $p<.0005$ ,  $n=41$ ).<sup>113</sup> Female patients received more LRD kidney offers from the younger generation than male patients (21 vs. 9 offers, respectively). In addition, male patients received more LRD kidney offers from contemporaries than female patients (61 vs. 30 offers,

<sup>113</sup> One patient was excluded from analysis because the potential donors were of uncertain number. The offers made by family or friends who were minors (n=10) were not included in analysis because they are unable to provide informed consent to donate. Thus these data reflect potential legal donor offers. In addition, donor offers made by kin of an unspecified number (e.g., daughters and siblings) to one male and one female patient were excluded from analysis.

respectively). Female patients received more offers from the older generation than male patients (22 vs. 12 offers, respectively).

Transplant professionals reported that they have also discerned the same distinct patterns in the kin relations between donors and recipients.<sup>114</sup> For example, parents are highly likely to offer to donate kidneys to their children (any age). Conversely, parents are highly unlikely to accept offers of kidneys from their adult children. Although many adult children offer to donate, most parent-patients refuse the offer because of their discomfort with the possibility of shortening their child's lives.

Why are children, in this case adult children, protected from possible harm that may occur from helping their parents with ESRD? An explanation is that we live in a youth-oriented culture (Feifel 1977; Jackson 1994). Studies of other medical practices have found that clinicians and patients are more reluctant to witness the death of pediatric patients than of elderly patients (Nelson, et al., 1995). In that study, for example, healthcare professionals considered it more emotionally difficult to write a do-not-resuscitate order for children than for adults.

When parents discounted their children as possible donors it seemed like they made their decision based on two assumptions. First, with regard to adult children, a good life is a long life, which may be difficult to attain by donating a kidney. Second, with regard to the patient, transplantation was seen as worthwhile having only if it provided many more years of life. However, a few patients (n=3), all men, felt that they did not have many more years left to live.

Patients' disinclination to accept kidney donations from their children may be influenced by transplant professionals' attitudes about it. For example, Dr. Varga, a transplant nephrologist related that he explicitly tells patients that he is one of a minority of clinicians who is opposed to

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<sup>114</sup> Transplant professionals did not comment whether these patterns existed similarly across ethnicities.

donations from younger generations to older generations for two reasons. First, chronic illnesses may emerge in young donors in their later decades. Second, since LRD transplants have been done for 30-35 years, there is relatively little data on long term adverse effects in a healthy donor. Other transplant professionals frame the LRD data in a positive way, that is, they believe that the 30-35 years of data sufficiently warrants the safe practice of LRD. According to the National Kidney Foundation (1993:27), the long term effects of uninephrectomy (removal of one kidney) on living donors have been studied for up to 25 years with no apparent detectable differences in longevity compared to a similar non-donor population. Transplant professionals thus have different interpretations of the long term data for living donors.

Transplant centers' opinions about using LRDs has also been shown to affect the rate of LRD transplants; positive opinions lead to higher rates (Sofaer, et al., 1997).<sup>115</sup> A small number of transplant centers in the US (5 of 211 surveyed between 1992-1994) do not perform any living donation transplants because of the ethical concern with harming the donor for no benefit to themselves (Sofaer, et al., 1997). The vast majority of transplant centers, while taking precautions to protect living donors from undue physical harm incumbent upon donating a kidney,<sup>116</sup> are more willing to perform LRD kidney transplants for the sake of respecting the autonomy of donors and recipients and increasing the number of kidneys available to patients for transplantation (UNOS 1992b). Living donor kidney transplantation continues to be a controversial topic, especially among unrelated donors because of the possible underhanded practice of buying and selling of organs (UNOS Update 1993; Bonomini 1991; Kreis1985).

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<sup>115</sup> Further research on whether transplant professionals' opinions about the nature of the relationship between potential donors and recipients affect the rates of LRD may also prove fruitful.

<sup>116</sup> UNOS points out that "the risk to the donor's life must be low (in the range of 1/1000 or less chance of mortality due to the procedure, estimated from the risk of death from undergoing general anesthesia alone, which is about 1/10,000)" (UNOS 1992b:2236).

### Deal with my problem alone: self-reliance

Seven patients (4 pro- and 3 con-transplant) explained that they would not accept a LRD offer because they would rather deal with their medical problem alone instead of imposing it on someone else. Patients explained this view in the following ways:

Michael: "My own problems are my own, other people (potential donors) don't have to suffer for me, I did it to my self."

Talmadge: "All my life I've done things for other people, not that I felt weak, I felt funny taking things from other people that I knew they needed... I wasn't being macho... I know they're doing swell. I told them [potential donors] no, I don't need anything. It's more important to me that they use their money better to serve them."

Pearl: "I just wouldn't [ask, but will accept my son's offer]. I just go through it by myself."

These statements attest to a 'rugged individualistic' approach to health care. Since the above quotes were all spoken by African Americans and primarily by men (n=6 of 7), there may be ethnic and gender issues underlying this trend. Specifically, males, particularly African American males, tend not to rely on others for health concerns, as has been shown in other studies (Henderson 1997; Zborowski 1969; Reed, et al., 1993). In fact, there were significant gender differences in accepting a LRD kidney offer among the pro-transplant group ( $X^2=6.469$ ,  $p=.039$ ). Although slightly more males than females were offered LRDs, significantly more females (n=13) than males (n=10) were willing to accept the LRD offer.

These statements also reveal the possibility that patients, by emphasizing self-responsibility for their own health, were protecting the potential donor from harm. Recall in the section on risk that patients also said that they would not accept a LRD kidney offer because they felt healthy enough to endure their ESRD: Virginia: "I can deal with this situation as is"; and Simon: "Not while I'm doing OK." Moreover, at least two patients (Talmadge, Richard) commented that kidney donation may be financially draining to the donor.

There were no significant relationships between the gender or ethnicity of the patient and the gender of the potential donor among pro-transplant patients. While not significant, more females than males had offered to donate; while most of the female patients received donor offers from females, most of the male patients received donor offers from males. These gender patterns in donation were supported by the experiences of transplant professionals. Transplant professionals generally agreed that there are more women donors than men. One study found that among spousal donors, 2.6 times as many wives as husbands were donors (Terasaki, et al., 1995). Terasaki and colleagues found that the survival rates were equivalent between wife-to-husband graft as husband-to-wife grafts if the wife had not been pregnant, however, the graft survival was worse if the wife had been pregnant. They did not explain the difference in rate of donation by gender. However, the difference may be due to the fact that more men than women have diseases causing ESRD, such as diabetes and HBP, so it is likely that their spouses, (most commonly) women, would come forward to donate.<sup>117</sup>

Another explanation for the high rate of women living donors may be attributed to dominant American cultural values of women as caretakers (Mintz and Kellogg 1988; Cott 1977). That is, women have traditionally been the ones to nurture their family members. Donating a kidney may constitute an extension of this care-taking role.

#### Conditional acceptance of kidneys

Seven patients (three pro- and four con-transplant) indicated that they were currently but temporarily reluctant to accept a LRD kidney offer, but that they would accept it under certain circumstances. Most of these patients were male (n=5) and all were African American (n=7). These patients said that if there was an emergency in which they were close to death, then they

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<sup>117</sup> Interestingly, spousal donation is prohibited by law in France (Souillou 1995). In 1994, in the US, 27% of transplanted kidneys come from living related donors, as compared with 4% in France (Souillou 1995).

would accept the offer. These patients thus preferred a CAD kidney (for reasons noted above) before resorting to a LRD kidney as a last chance to obtain a transplant. Patients implicitly conveyed the notion that they could hold out and delay a LRD transplant while acknowledging that a ‘spare part’ is available upon request. The following statements indicate the conditions in which patients would accept a LRD kidney:

Samuel: “She [patient’s mother] said she would [donate] if I got worse. I know she would. I don’t want her to do it. I’d rather have dialysis. I’d rather wait ‘till I really need it (I really need it now) but ‘till an emergency situation... when push comes to shove... [A LRD organ would be] asking for an organ that I don’t really need. If it’s an emergency situation, I don’t think I’d have to ask, they’d come to me.” According to this patient, an emergency would be if he became real sick, had back pain, and could not walk.

Monique wanted to wait until after she received a CAD that rejected to accept her brother’s kidney offer. She wanted to wait three years for a CAD (2 years had already passed) or until she became “frustrated with dialysis (which I doubt)” before accepting his offer. Her reason for waiting was because she feels “O.K.” but would accept the living donor offer later “in an emergency if something came up” or if she “needed it right away.”

Interpersonal family tensions also played an important role in patients’ reluctance to accept a LRD kidney offer. Eight patients (5 pro- and 3 con-transplant) explained that they were offered a LRD kidney but were not willing to accept it under the conditions specified by the donor. These patients were evenly divided by gender and were mostly European American (n=5). For example, Malcolm’s sister offered to donate, and even went to get tissue typed (the match was no better than a CAD), but her husband (a former friend of the patient) would only allow her to donate if she never spoke to Malcolm again. Malcolm refused to accept this condition and thus his sister’s kidney offer. In reference to that scenario, Malcolm thought aloud, “You can keep your organ, I don’t want you to run my life.”

Other patients hinted at the possible emotional and even financial pressures they have already felt or might feel by the donor if they accepted the kidney offer. For instance, Bruce explained that he refused to accept a kidney if his son or brother offered because “I don’t want to hear about it later. If I get a kidney elsewhere I will never hear about it again.” Bruce noted that

they would likely say things like, “If it wasn’t for me you wouldn’t have a kidney... [So] I’d tell him to keep his damn kidney.” Juliet similarly noted, “I would feel like I owed him [her husband] for the rest of my life” and she would have a “guilt complex” if she got into fights with him. Barbara also relayed what she did not want to happen if her children donated: “I don’t want you to look at me and say, I make you survive because of my kidney.”

Another patient, Gina, explained why she refused to accept her daughter’s kidney offer in terms of financial pressures. Although her youngest daughter was a good donor match, Gina refused to accept the offer because her daughter “kept talking about covering her expenses while in the hospital, paying her wages” which made Gina feel like her daughter was “selling her kidney.” Gina contrasted the younger daughter to the older one whose kidney she would have accepted (if it was a match) “because I know truthfully that she wanted to do it. She’s a giving person... [It] was a gift.” Two other patients (Roy and Clarence) explained that they had gotten into arguments with their potential donors and consequently changed their minds about accepting the kidney offers because of their strained relationships. Other research has shown that family tensions affect potential LRD decisions (Simmons, et al., 1971).

### **Asking For a LRD**

Another variable examined was whether patients would ever ask anyone to donate. Only 17 (21.5%) patients of the entire sample would ever ask someone to donate. Specifically, 22.4% (n=11) of the pro-transplant patients, and 20% (n=6) of the con-transplant patients would ask for a LRD kidney. There were no significant differences by treatment decision, ethnicity, education, gender, income, and religion in willingness to ask for a LRD. Of the pro-transplant patients who were offered a kidney and plan on accepting it (n=23), only a third (n=7) would have ever asked people to donate to them. Thus apparently, patients perceived a difference between asking

someone to donate and accepting someone's kidney offer. This difference is best explained by two major issues patients raised: (1) asking people to donate is difficult to do, and (2) asking people makes them feel obligated to donate which is not good because organ donation should be voluntary. These two issues are examined below.

#### Too difficult to ask

Patients did not want to ask anyone to donate a kidney because they considered asking to be a 'big' and difficult thing to do. Nine patients (7 pro- and 2 con-transplant) stated this. Most patients were female (n=5) and African American (n=6). Patients conveyed this idea in the following ways:

Fatima: "[It is] difficult to ask because it's a really big favor."

Janet: "It's just not me... I mean that's asking an awful lot to ask them for their kidney!"

Simon: "I wouldn't just ask nobody. That's not the easiest thing to do. No matter how much they love you, they be scared to death."

As these statements show, regardless of the love between the patient and potential donor, patients perceived a limit to what people can offer as far as 'favors' go. Perhaps the perception of asking as being difficult can be tied to gift-giving dynamics, as elaborated by Fox and Swazey (1992) and discussed in Chapter 1. Patients in this study might experience an underlying sense that they do not have a substantial enough gift to offer potential donors as enticement to go through with the donation. The term 'favor' usually means that two people alternate in giving each other aid or gifts over time. By using the term 'favor,' patients may have believed that asking for a kidney was too substantial a request or favor to warrant the gift because past favors on the part of the patient were not, or could never be, as grandiose.



### Donation should be a voluntary act, not an obligation

Ten patients (6 pro- and 4 con-transplant) were reluctant to ask people to donate to them because of their expectation that a kidney offer should be a voluntary act. Most of these patients were male (n=7), African American (n=5), and European American (n=4). Patients implicitly maintained that the mere act of asking someone to donate obligates the potential donor into going through with the surgery. Phrases such as “feeling pressure” or “pushed into donating” reflect this notion. Patients clearly expressed discomfort with this possibility. The following statements exemplify the link between obligation, voluntariness, and emotion involved in asking someone to donate:

Allison: “It’s a totally voluntary thing. It’s a gift. It’s not something to ask someone. I would educate and tell them but not ask... [I wouldn’t want someone to feel] obligated to do something like that.... If somebody wants to do that, they’ll offer. I wouldn’t want to put somebody in that position if they didn’t really want it.”

Roland: “I never would have asked them... Something like that needs to be volunteered... [otherwise it is] not from the heart... It’s like feeling pressure to do it [donate].

Irving: “I feel it’s... I don’t want to put them in a position where they feel obligated.”

There are many facets to patients’ reluctance to accept or ask for a LRD kidney. Transplant professionals reported that other ESRD patients commonly voiced the same concerns about risks to the donor, even in the order presented above. Yet worthy of closer inspection is the emphasis patients in this study placed on the potential donor. Patients rarely mentioned anything about the effect of having a kidney from a living donor on themselves. The only partial exception is when patients asserted how ‘guilty’ they would feel if the kidney rejected. In other words, patients did not express concern about their own well-being should they accept a LRD kidney offer.

## **Methods of Increasing LRDs**

Transplant professionals, recognizing patients' discomfort with asking family members to donate, have developed ways for patients to raise the issue of LRDs with their family without pressuring them to offer. Dr. Gilmore related how he encourages patients to consider LRD:

"Well I try to let them understand that being a transplant donor is a limited situation. This... person who gives an organ gives them a sense of self-worth that they've helped someone else, obviously the recipient, it helps them by getting them off dialysis. And you got to make them [patients] understand that we thoroughly evaluate the donors to make sure that there's no ulterior motives and this is truly a selfless position on the part of the donor who gives the kidney, they obviously don't expect anything in return, and most people are willing to donate because of their sense of commitment to the recipient."

Dr. Ingel tells patients to present the idea of LRD to their family in the following way, and provided pointers afterwards:

"I met with my doctor, and he was discussing some of my treatment options, including staying on dialysis or going for a kidney transplant, which may either be from a cadaver or from a living donor.' And just describing that as you would discuss something else, and not really ask someone. And, many times then someone who would be potentially interested as a donor will then just speak up at that time, and say, 'Well, I'd give you a kidney.'"

This nephrologist also discourages patients from using the phrase "My doctor says I need a transplant" because it is coercive. Transplant surgeon, Dr. Riley revealed his method of encouraging patients to talk to their family about LRD:

"...And so the way you get around that is you say, 'Listen, they want to provide a gift to you, and that's something that you shouldn't deny. That the bottom line is that medically, a donor for kidney transplant is just as healthy as anyone else and that there are many people who go their whole lives with one kidney and don't even know it. They've been studied for over 45 years and they have no increased incidence of renal disease or any other disease having just one kidney. And that there's absolutely no risk or harm if you perform a living donor [transplant], and nobody has ever died from the surgery, and that we'll do everything we can to keep that record strong. This is definitely something that is a wonderful gift and you shouldn't deny their right to at least give that to you, and to consider it strong.' That usually turns a lot of heads. Then the second issue, when you're dealing with the individuals that have said, 'I don't know how to bring it up, I don't want to put anybody under pressure, I can't just go asking,' I tell them, 'You tell them Dr. Riley told you all about this stuff and that we sat down and we talked long and in detailed fashion about the kidney transplants.' I say but be sure to emphasize to them that I mentioned there were two kinds of kidney transplants, the living-donor, the cadaveric, tell them that the benefits of the living donor are that they're the best kidney transplants you could ever get. You could schedule it, we could do it in just a few months, and you could be immediately with a good kidney function that lasts longer and have better function in the year down the line than any other kind of kidney transplant. You just leave it there and drop it. If they are interested, or they want to volunteer to have it done, they may bring it up, otherwise, you haven't asked them, you haven't said a word, you provided them with information. I say to also mention that the cost for the donor is totally defrayed by the recipient's health care provisions, even Medicare pays for everything, including the labs, the x-rays, and the surgery, and the post-operative care, it includes it all by the recipient, so it's at absolutely no cost, and if the

donor does not have health care in order to be able to be a kidney donor. So usually if you put it that way, you find out there's a lot of the living donor possibilities..."

These suggestions embody the ideology of kidney donation as a voluntary act. In addition, these suggestions imply that recipients should not prevent their family from giving them such a gift by not discussing the treatment options with them. They all emphasize the strategy whereby patients straightforwardly present information to their families about various treatment options, risks, even financial issues, and leave it at that. Ensuring the potential donor's voluntariness therefore means informing them about ways of helping the patient and letting the family take up the issue on their own.

### **Factors Precluding the Use of LRDs**

Despite transplant professionals' efforts at helping patients to 'ask' their families to donate, there are patients who, for various other reasons, are unable to receive a LRD kidney. Some patients are not as fortunate as others to have a choice in their donor source because LRDs are not available to them or because there are logistic and medical factors that make kidney donation from family members infeasible. With regard to logistical problems, some patients simply have few or even no family members to consider as possible donors. Others are fortunate to have large families which technically increases the chance of having a greater number of potential LRDs. But even large families do not necessarily bode well for the availability of LRDs.

Family members may be too sick, too old, or too young to donate a kidney to a loved one. Since various causes of kidney failure (e.g., diabetes and hypertension) are hereditary, potential donors in a family may be medically unable to share their kidney with the patient. This is particularly the case among African Americans who have a high incidence of these diseases.

Although they may be healthy enough, some family members may be reluctant to donate because of their fears of surgery, uncertainty about future health, and missing time from work to recover from the operation (Youngner 1992; Simmons, et al., 1971). Transplant professionals frequently commented that family members often offer to donate but fail to even begin or complete the testing process, thereby frustrating patients by generating false hope. A patient explained why he refused to ask his siblings to go through with the donation after they offered:

Emmanuel: “They already offered to go but never got off their butts to find out information and get [tested to be a match]. I left it alone... I’m not going to ask anymore. It’s a waste of time. If they’re going to do something for you, they’re going to do it... I gave them most information about it, they didn’t call – I can’t beg them.”

This section shows that patients weigh the benefits and risks of living donation on the donor and on interpersonal dynamics in their decisions about accepting or asking for a LRD kidney.

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## **CONCLUSION**

In this chapter we have examined additional treatment-related decisions patients make for ESRD. We have seen that patients’ own decisions about accepting or asking for a living (related) donor kidney, and accepting or turning down an offered kidney, play a role, albeit relatively small, in their access to transplantation. As we saw in Chapter 7, patients’ decisions ultimately effect the number and ethnic composition of people who are listed for a kidney transplant. In the following two chapters we will look more closely at how healthcare professionals’ clinical practices and treatment decisions may influence patients’ access to transplantation. The next chapter follows in a chronological sense the events that occur after patients make their treatment decisions known to their nephrologists.

## **CHAPTER 9: NEPHROLOGISTS' REFERRAL OF PATIENTS TO THE TRANSPLANT CENTER**

In the previous two chapters we learned how patients make decisions about their treatment for ESRD. In the course of their routine visits with nephrologists, patients indicate their treatment preferences. Once nephrologists discover that patients are interested in seeking a transplant, they must decide whether to refer patients to the transplant center. This decision-making process is influenced by a variety of factors: legal, financial, patient-specific, and cultural. Thus, this chapter uses cultural constructivism as a tool for analyzing the assumptions that guide nephrologists' decisions.

In this chapter we will see that nephrologists' decisions about referring patients for transplantation subtly render them in the role of "gate keeper" to kidney transplantation, as was initially examined in Chapter 6. By considering nephrologists as "gate keepers," we readdress the possibility that their decisions about referral to transplantation affect patients' access to kidney transplantation. Examining how nephrologists decide whether to refer patients to transplantation reveals whether they engage in steering patients to one therapy or another.

This chapter is organized into two main sections. The first section focuses on how nephrologists decide to refer patients to the transplant center in consideration of the various factors listed above. This discussion covers the incentives and barriers to patient referral. We will see that without standard guidelines, nephrologists rely on what they consider important patient characteristics, e.g., issues of compliance, to determine whether and how to refer patients. Deconstructing the concept of compliance will help us to understand why it plays a crucial role in nephrologists' referral decisions.

The second section considers how other dialysis clinicians, namely, nurses and social workers, communicate to patients about their treatment options decide whether to refer patients for transplantation. The variation in ways in clinicians' communication practices and the extent to which they cohere with legal regulations will be presented. Dialysis clinicians' referral practices will be also shown to be shaped by views about noncompliance shared by nephrologists.

### LEGAL BACKGROUND

Since 1974, nephrologists are required by Medicare to annually review a list of their patients<sup>118</sup> and their treatment choices as a safeguard to ensure that patients get referred for a transplant if they are eligible for one (Office of Inspector General 1987). The annual review process involves updating a patient's long term care plan, a form specifying a patient's transplant status, based on changes in a patient's medical status and/or treatment preferences made known at recent clinical encounters. The responsibility for oversight of dialysis facilities to develop patient long term care plans rests in the State survey agencies and the ESRD network organizations (Office of Inspector General 1987:6). The government also requires the dialysis team to meet about each patient's short-term care every six months.

The Medicare mandate to review patients annually for a transplant was established to facilitate equitable access to transplantation by ensuring that nephrologists refer patients to transplant centers. This law seeks to prevent nephrologists from maintaining patients on dialysis for nephrologists' own benefit. According to Dr. Alland, this law was set up "because of some sense that nephrologists were hoarding patients which was crazy." The medical director who

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<sup>118</sup> Nephrologists are legally required to begin reviewing new ESRD patients' long term care 90 days after each patient starts dialysis.

established the CDCs, Dr. Mori, quipped that for the same reason, the LTCPs are “built on paranoia.” Even with this law in place, the OIG found that some dialysis centers referred patients at considerably low rates (Office of Inspector General 1987).

Nephrologists organize patients’ treatment choices into five categories, which are emically denoted as: a) candidate for a transplant and wait-listed, b) candidate and in process of evaluation, c) candidate but uncertain,<sup>119</sup> d) not a candidate because patient refused, and e) not a candidate because patient is medically unsuitable. For patients who are not candidates for medical reasons, nephrologists must specify the exact problem on the long term care plan, e.g., cardiovascular disease, cancer, age, etc. Nephrologists are required to refer to transplant centers those patients who are categorized as candidates. Dr. Julian explained the process of annually reviewing his patients in the following way:

“The need to annually review the status of all patients drove this whole system. I mean the dialysis units were told that they had to re-review the transplant statuses of every patient, even if they’ve been ineligible because they’re 80 years old for the past 10 years, you have to re-review it. ... Now the primary nephrologist is asked each year to review his own patients just to make sure their transplant statuses are up to date. And then they generate this huge list of all their patients. And I’m given a list of every patient under the AH designation and I have to sign off on that. Frankly it’s pretty meaningless because there are so many patients. But I do go through the list one by one and what I have to do is focus on the undecided group and then I also go through the ineligible group and make sure that there’s nothing that slipped through the cracks. A lot of times, the reason for ineligibility isn’t indicated. If it’s an 80-year-old patient, I’ll just write presumably age. But occasionally I’ll see a 40 year old patient ineligible [for] no reason. And I actually get back through the medical director and ask that the primary nephrologist address that and to change the status. So there’s a pretty good system in gear...”

This excerpt is especially revealing about the annual review system because the nephrologist contradicted himself when he said early on that “Frankly it’s pretty meaningless” but concluded by noting, “So there’s a pretty good system in gear.” While such contradictions or contested knowledge of medical practice are common (Lindenbaum and Lock 1993), they illuminate the cultural processes at work to deal with situations of uncertainty. The uncertainty here pertains to whether the annual review system works well enough to ensure proper referral of patients to

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<sup>119</sup> A patient categorized this way means that she or he is uncertain about whether to get a transplant.

transplant centers. A discussion with Dr. Mori revealed similar feelings about the usefulness of the annual review system. He noted that while the annual review system generally works, it is “annoying” for nephrologists to review their patients, especially since the problem with access to transplantation is primarily a matter of limited numbers of kidney donors.

With these legal guidelines in place, the likelihood of not referring patients to a transplant center for illegitimate reasons is minimized. Why would patients not be referred for transplantation? There is evidence that over the past two decades healthcare professionals were not unified in their attitudes about kidney transplantation, possibly because the outcome data were not as good as today. In the early 1980s, nephrologists and surgeons believed that their own subspecialty optimally treated ESRD (Plough 1981:90). In the Inspector General’s (1987) report, there was evidence of nephrologists continuing to have reservations about transplantation as an effective treatment. Thus such nephrologists are less likely to refer patients to receive that therapy. Based on the medical literature and interviews, it appears that most, if not all, dialysis professionals now concur that transplantation is the most optimal treatment for ESRD.

Yet another major factor believed to influence nephrologists’ referral rates is financial incentives. The initial cap or ceiling price that Public Law 92-603 established was \$138 per treatment to freestanding facilities, and \$159 on average, to hospital-based facilities (Lowrie and Hampers 1981). However, in August 1983 there was a cutback in reimbursement for dialysis to \$122 per treatment at freestanding facilities, and \$126 at hospital based facilities (Daniels 1991). Whereas physicians are reimbursed between \$1,584-\$2,436 per patient per year; hemodialysis facilities are reimbursed \$20,280 per patient per year (Nissenson, et al., 1993).

Physician reimbursement is the same for HD as for PD since a monthly capitation fee covers all dialysis-related services (Nissenson, et al., 1993). Since these rates have never been



adjusted for inflation (Rettig 1991), there is cause for concern that nephrologists somehow seek increased financial compensation. There is the suspicion that nephrologists who own hemodialysis facilities have a financial incentive to direct their patients to HD instead of PD and possibly even transplantation. From a business perspective, it is important to keep hemodialysis facilities as full as possible to maximize profit. Physician bias may be transmitted directly or indirectly to patients when selecting a treatment modality. Patients often ask physicians to make the best decision for them since new ESRD patients are not fully informed to make such a choice (Nissenson, et al., 1993).

There are more suspicions and allegations of nephrologists' financial incentives to not refer patients than there is evidence of its occurrence. Some clinicians, including transplant surgeons, believe that by referring patients for transplantation, "nephrologists take the chance of losing income. In a newer facility trying to get established, a proprietary one owned by nephrologists, or one having a difficult time maintaining its caseload, this financial factor, some feel, may be particularly important" (Office of Inspector General 1987:6). Nephrologists and dialysis social workers reported anecdotal evidence during informal interviews that there are one or two nephrologists in this city who fail to refer their patients for transplantation. A typical sign of this practice is when patients are told that they are required to remain on dialysis for a year before their physician will refer them to a transplant center.<sup>120</sup> Dr. Julian explained how he came to learn of this practice:

"Patients will tell us that Dr. so and so has advised against transplant or had given them absolute wrong information about who's a candidate for a transplant. We know of physicians on the committee who told patients that they can't have a transplant until they've been on dialysis for at least one year, which is completely fallacious."

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<sup>120</sup> Dialysis nephrologists and social workers expressed disapproval of nephrologists who engage in this practice. It is unknown how they respond to nephrologists who engage in this practice. However, a comment from a dialysis social worker suggests that social ostracism occurs. This social worker remarked that such nephrologists are forbidden from entering the dialysis center in which she works.

This practice generates much suspicion about such nephrologists' intentions. The practice may have been more likely to occur in the past, explained Dr. Ingel because "we weren't starting people on dialysis until they were very uremic and there may have been a period of time that they were malnourished when they came into dialysis and it allowed some stabilization period." Despite medical contraindications that may in fact warrant time on dialysis, the wait for referral to a transplant center would have been a much shorter period of time, such as one or two months.

While most nephrologists deny such assertions of illegal practices, many are concerned that patients referred to transplant centers are a "captured" population (Office of Inspector General 1987:6). Transplant surgeons tend not to refer patients back to the nephrologist for the management of their renal disease following their transplant (Office of Inspector General 1987:6). Transplant professionals explained this trend in terms of patient preferences. That is, patients prefer to have their renal disease followed by the transplant nephrologist because it prevents fragmentation of their care. Dr. Julian explained this trend further:

"And, unfortunately it's true that once patients are transplanted, they become attached to the transplant center. And even when we try to refer the patients back to their primary nephrologist, I mean you're stable now, you can go back to them, a lot of patients refuse to go back, they just feel like they become too attached to the transplant center or would rather have all of their care funneled through the transplant center. Many of them perceive that all we're doing is double billing by having them go back to their primary nephrologist."

#### NEPHROLOGISTS' REACTIONS TO THE MEDICARE LONG TERM CARE PLAN POLICY (LTCP)

Six nephrologists made comments indicating their awareness of the potential for financial incentives to influence nephrologists' referral practices.<sup>121</sup> The discourse about financial disincentives for transplant referral is so pervasive and significant that it even influences

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<sup>121</sup> Dr. Julian and Dr. Ingel both noted that some of their patients indicated they were suspicious of nephrologists being "cash cows." Innumerable patients on the Internet have made countless comments over the past two years indicating their suspicion of nephrologists treating patients in ways that render them "cash cows."

nephrologists' actual referral practices. Dr. Nicola made the connection explicit that nephrologists refer most of their patients -- even medically uncertain ones -- to prove that they are not financially motivated in practice. Four nephrologists acknowledged that they wanted to avoid bias of their own when referring patients because they are not experts on transplantation. Here are some statements nephrologists made in these regards. According to Dr. Nicola, HCFA and Medicare think that nephrologists in general under-refer. In response to this notion, he said:

"I'll refer more patients than who are medically eligible. I'll send them over to remove any doubt of being not exactly right about their medical status, and also to counter the idea that nephrologists do not want to refer patients to keep them in their NDCs for financial reasons."

Other nephrologists similarly commented:

Dr. Varga: "Even people I think who medically wouldn't be a candidate because they got diffuse cardiac disease or athrosclerosis or other medical problems, I usually end up letting them go anyway and having a transplant physician make a final decision about whether the person should be in the program or not so that I don't introduce any of my bias, but let somebody who's an expert make the final decision about whether they are medically cleared to undergo a transplant."

Dr. Olson: "I usually refer all of my patients over there and let the transplant nephrologists do it. ... So my decision is not linked to are these people going to be accepted or rejected as a candidate for transplant... So I usually send all my patients over there... unless they're medically ineligible because of age. I always try to get them all over there so they can at least hear all the information from the people in transplantation and make an informed decision with the best available information. So I try not to be paternalistic and accept or reject people for transplant up front, they all kind of go over there."

As these statements show, nephrologists' current referral practices appear to entail a nonrestrictive flow of patients toward the transplant center since they have internalized the need stipulated by HCFA policy to refer patients for transplantation. What remains to be explained is the discrepancy between the fact that the OIG found low rates of patient referral to transplantation and the data presented here which suggest high rates of referral. The discrepancy may, in fact, be explained by nephrologists' decision-making practices about barriers to referral. The following discussion reviews some of the barriers to referral with a focus on noncompliance as a key consideration.

## **BARRIERS TO PATIENT REFERRAL TO TRANSPLANT CENTERS**

The factors preventing nephrologists from referring patients to the transplant center can be examined in two ways. One way involves understanding nephrologists' impressions about the suitability for transplantation of specific patients included in this study. The second way entails describing their views about barriers in general.

### **Nephrologists' Views about Specific Study Patients**

The purpose of this section is to show how AH nephrologists' decisions about referring their patients for transplantation are, in part, influenced by patients' sociocultural factors. Below are some of the comments four nephrologists made about 57 of 60<sup>122</sup> AH patients included in this study. The nephrologists rated how good these patients would be as transplant candidates between 1 and 5 (a score of 5 is the best; a score of 1 is the worst).<sup>123</sup> The way nephrologists rated patients and explained the basis of their rating suggested that they viewed patients as falling into one of two categories: those who are rated '4' or '5' and those who are rated '2' or '3.' Nephrologists' scores of patients decreased as patients presented more medical and compliance problems.

There were no significant differences in patients' gender, age, ethnicity, education level, income, and SES in how nephrologists rated patients. Nephrologists rated twelve patients a '5', twenty-one patients a '4', sixteen patients a '3', seven patients a '2', and one patient '0.' The majority of patients rated '5' and '4' were female (7 vs. 5 for '5' and 13 vs. 8 for '4'), yet the majority of patients rated '3' or below were male (9 vs. 7 for '3', 4 vs. 3 for '2'). Those rated '5'

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<sup>122</sup> Three patients were not included in this analysis because one was of a different doctor, one was recruited after this rating task was performed, and one was rated as unknown by her doctor because she never came to her clinic appointments.

<sup>123</sup> Since nephrologists gave decimals, I rounded these numbers up for analysis purposes.

were evenly distributed among age categories. The majority of those rated '4' were in the age categories 40-49 (n=5) and 60+ (n=7), but were otherwise evenly distributed in the other age categories (n=3). The majority of those rated '3' were in the age range 40-49 (n=7), with even distribution from age 30 and up. Patients rated '2' were evenly distributed from age 30 and up. Since the ethnic composition of AH patients was highly uneven, with seven European Americans and fifty African Americans, it is best to speak in broad strokes. The majority of African Americans were rated '4' (n=20) while the majority of European Americans (n=3) were rated '5.' The majority of patients rated '5' had some post-secondary education. The majority of patients rated '4' were high school graduates. Those rated '3' were evenly distributed in their educational background. Most rated '2' had some post-secondary education. Lastly, the patient rated '0' had less than high school education.

Nephrologists rated patients a '5' because such patients are medically excellent candidates with no other underlying diseases. For instance, nephrologists rated patients a '5' because they were:

"Very young and healthy, he wants to be active, high motivation."

"Compliant, bright enough to follow, shows up for office visits, no significant underlying issues."

"She's well-adjusted to renal disease, young, healthy, bright, a student, highly compliant, motivated. She calls if she has a problem, she's the easiest patient."

Those patients who received a rating of '5,' as these brief representative explanations show, share several traits. First, younger and healthier patients were given a high rating. Second, compliance behavior is essential to nephrologists' evaluations of good transplant candidates because of the understanding that it predicts post-transplant compliance.<sup>124</sup> Third, patients' motivation to get a transplant, and less so intelligence, played a large role in nephrologists' rating

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<sup>124</sup> The importance and cultural understandings of compliance are presented in the next section.

system. One nephrologist explained that “Motivation is essential. You can’t give a transplant to someone whose arms and legs are waving.”

Nephrologists rated otherwise medically excellent candidates a ‘4’ or ‘3.5’ because such patients presented a history of noncompliance. For instance, one nephrologist commented that a patient raised “some compliance questions but [was] physically fine.” Another patient was rated 3.5 because he was “noncompliant otherwise medically he’s an excellent candidate.” Knowledge of the patient’s personal background or personality also factored into nephrologists’ assessments of patients’ suitability for transplantation. Nephrologists’ statements to this effect include:

“She has lupus but no underlying medical problems. A lot of depression. She’s made substantial gains in the past year in terms of physically and psychosocially.”

“Physically there’s no reason to not get a transplant. He’s an angry young guy, angry with dialysis.”

“He doesn’t keep his office visits, he doesn’t stay his prescribed time on dialysis but for compelling work issues, his kt/v is low.”

In a way, knowing something about the patients’ life situation, e.g., that the patient must leave dialysis promptly to get to work on time, seemed to temper nephrologists’ negative assessments of noncompliant patients. Patients were rated ‘4’ instead of ‘5’ when their mental status raised a serious concern about whether patients could be compliant post-transplant. According to one nephrologist, a patient was a “4.5 -- good candidate but less .5 because he does not have a good understanding of things. He might get his medicines mixed up.” Another nephrologist rated a patient ‘4’ “because she does not take her phosphate binders, but I don’t know if that translates to not taking immunosuppressant drugs.” Other patients received a score of ‘3.5’ or ‘4’ because of their medical problems: “She has diabetes but that’s really it. She would do better with a transplant than dialysis. She has access issues.” In addition to medical problems, patients who do not express clear motivation were also rated lower. For instance, consider the two statements

nephrologists provided: “3-4 because of cardiomyopathy and other medical problems, equivocal” and “3-4 because her age is against her. She’s older, always been ambivalent.”

Nephrologists rated patients a ‘3’ or ‘2.5’ especially because they are either very noncompliant or have medical complications, or both. Statements that illustrate nephrologists’ perceptions of such patients are as follows:

“3 He has been a polysubstance abuser which probably will affect his long term success with a transplant.”

“3 Because [the patient] does not show up for appointments, compliance issues.”

“3 He misses office visits, BP is not well controlled, no underlying medical circumstances, question of marginal resources, compliance, character.”

Nephrologists’ statements reflect their awareness of more than just their patients’ medical problems. Knowledge of patients’ psychosocial background and behavior are clearly incorporated into nephrologists’ assessments of what kind of person would make a good transplant candidate. Nephrologists rated one patient a score of ‘0’ because he never came to an office visit. Nephrologists were reticent about assessing patients who rarely came to office visits even though such patients “looked good on paper.” In sum, this exercise proved useful in gaining insight into nephrologists’ perceptions of their patients as potential transplant candidates which showed that nonmedical considerations factored into nephrologists’ assessments.<sup>125</sup> It is unknown whether performing this exercise effected nephrologists’ actual treatment or referral of the patients rated.

### **General Views about Barriers**

Nephrologists routinely decide whether patients are eligible or ineligible for a kidney transplant and thus referral. Nephrologists may find patients ineligible for a transplant for

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<sup>125</sup> As noted previously, there are no established guidelines on the referral of patients to transplant centers. Consistent with this absence is the lack of medical literature critically examining referral practices. Thus, there are no other examples upon which to draw to further discuss nonmedical considerations in nephrologists’ referral practices. This dissertation research is the first known study to address this issue.

several reasons, including, medical, psychiatric, drug use, and noncompliance problems. Since there are no standard methods used to determine eligibility for transplantation, there is somewhat of a margin of flexibility in their assessments of patients.

### Medical problems

The main reason nephrologists do not refer patients is because they have medical problems. Patients are medically ineligible if they have cardiovascular disease, cancer, drug addictions, infections like HIV, and are too obese or too old to undergo a transplant. As two nephrologists made clear, the medical criteria are not always cut and dry, and some element of physician judgment enters into the decision making process about referring patients to transplant centers:

Dr. Olson: "If they're interested in transplantation, if they're under 72 years of age, if they don't have an active, ongoing malignancy, if they're demented and have multiple strokes or are confined to bed in a nursing home, those people would be obvious. But there's not a list of criteria. You kind of look at the patient, make an assessment. But I always raise the issue or lots of times patients will raise the issue. So I would say, probably 80 or 90% of the patients who are on dialysis, this is one of the first things they do and we usually try to address this right up front pre-end stage renal disease, and not wait until they get onto dialysis and say 'now that you've been here for a couple of years, what do you think about a transplant?' Something to address right from the get go."

Dr. Ingel: "[For] the younger person in that group, I'll probably have a different approach than [for] the sixty five year old in that I usually then would say, 'I still think it's worthwhile for you to get on the transplant list because you're blood type O and it will be 5 years before you get a kidney, and five years from now you might feel differently, and because then you're not be able to do the things you want to do.' So, I do have somewhat of an age bias but it's I think relative and not arbitrary as far as an absolute age."

It is surprising that there is no list of criteria used by nephrologists to evaluate whether to refer patients for transplantation. The absence of such a list means that physicians' evaluations are susceptible to personal and cultural partiality. As was discussed in Chapter 6, nephrologists' decisions about information-giving are likewise shaped by sociocultural notions about the meaning of information. Similarly, we will see in Chapter 10, how sociocultural and personal beliefs about justice inform transplant professionals' decision-making process. In addition, without a standardized list there is likely to be inter-physician variation in referral practices.



These two excerpts also reveal how evaluations of patients' age rely on other patient factors, including health status, physiological constants such as blood type, and patients' preferences.

### Psychiatric and drug problems

When patients have severe psychiatric problems, nephrologists may wait to discuss and refer patients for transplantation until they become psychologically stable. Psychiatric problems include dementia and schizophrenia, and in lay terms they include nervous breakdowns, hallucinations, anxiety and crying, forgetting where you are, and delirium. For instance, Dr. Nicola recounted how "One woman patient was crying for a long time and very anxious about being on dialysis, so I did not discuss transplantation with her until she became stable and more adjusted to this treatment."

Nephrologists claim that patients' psychiatric and drug problems do not prevent them from referring patients, but, as Dr. Nicola pointed out, "they are finer points used in weighing patients after considering their medical status." In other words, nephrologists may alert the transplant center about patients with these problems. The reason for this is the belief that psychologically unstable patients are not going to be compliant with taking their transplant medicines. Similarly, a nephrologist explained that it is important to be sure that the patient is not a substance user because their behavior is not entirely predictable. Patients under the effect of drugs may damage themselves and may miss taking their immunosuppressant drugs, which increases the risk of losing the graft, as Dr. Avi noted. In other words, patients who engage in behaviors that are perceived to increase the risk of kidney rejection, should they receive a kidney, are less likely to be referred for transplantation. Contrary to these reports, a review of LTCPs at

a dialysis center shows that patients are considered ineligible for a transplant due to psychiatric problems and drug abuse.<sup>126</sup>

### Noncompliance<sup>127</sup>

Noncompliance is a significant factor influencing nephrologists', dialysis clinicians', and transplant professionals' evaluations of dialysis patients' eligibility for a kidney transplant. The issue of noncompliance warrants lengthy discussion because there was considerable talk or "discourse" about noncompliant patients among virtually all clinicians consulted in this study. This discourse signified moral tension about giving scarce kidneys to patients who show that they cannot take "appropriate" care of themselves.

In other words, it is argued here that nephrologists' moral animosity toward noncompliant patients affects their referral practices. Compounding the tension is the problem with uncertainty in identifying noncompliant behavior. In order to examine this discourse and the tension it represents more clearly, we begin by reviewing the empirical literature on the incidence of noncompliance among the ESRD population, the problems involved in measuring noncompliance, the demographic patterns of noncompliant patients, and the cultural deconstruction of the concept of noncompliance. This review is followed by nephrologists' reports of the effect of noncompliance on their referral practices, and the moral dilemmas raised by referring noncompliant patients.

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<sup>126</sup> The concerns over drug and psychiatric problems will be presented in greater detail in Chapter 9.

<sup>127</sup> Because the term 'noncompliance' is an emic term, I use it to better describe the worldviews of my informants. Because the term implies "a difference in power or authority between advisor and advisee" the term 'non-adherence' has been proposed instead (Chrisman 1977:368). Throughout this research, only one health care professional used 'adherence.' Regardless of the term used, most nephrologists and other renal health professionals conveyed a set of shared meanings that underscored the differences in power and moral tensions between themselves and noncompliant dialysis patients.

Noncompliance can be defined as “the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” (Haynes 1979:1-2). Noncompliance has been found to exist on a large scale: approximately half of all types of patients do not comply with their medical regimens (Zola 1980; Ley and Spelman 1967; Conrad 1985). Noncompliance among ESRD patients is also common; a literature review shows that noncompliance occurs in 30%-60% of dialysis patients (Wolcott, et al., 1986).

Many dialysis patients are noncompliant with their different treatment regimens, including dietary restrictions (limiting protein, sodium, and potassium intake); medication restrictions (to compensate for kidney failure and to manage underlying comorbidities); and fluid restrictions (to compensate for the kidney’s inability to excrete fluids) (Bame, et al., 1993; Wolcott, et al., 1986). Not showing up for clinic visits with nephrologists, or for hemodialysis, and cutting dialysis treatment short also constitute forms of noncompliant behavior. A study of the prevalence and reasons why patients sign-off early from and not show up for hemodialysis treatment found that one-third of patients (n=231) engaged in these behaviors over a 12 month period (Rocco and Burkart 1993). The study found that 35% of all early sign-offs were due to personal reasons and noncompliance. Personal reasons included personal business or errands, appointments with other healthcare professionals, and family responsibilities (e.g., cooking dinner, visiting family members in the hospital, and providing transportation to other family members). While the medical and dialysis reasons for early sign-offs are considered acceptable reasons, personal reasons are not because they are perceived as “within the patient’s control” (p.1181) and thus preventable. Patients tend to be noncompliant with some regimens more than others. For instance, one study of hemodialysis patients (n=1230) found that few patients (10%)

were noncompliant with their diet regimens, but half were noncompliant with medication taking and fluid restrictions (Bame, et al., 1993).

Patients' noncompliance is of concern to healthcare professionals because they contend that it can adversely affect patients' health. Clinicians are especially concerned with dialysis patients' noncompliance if they are interested in seeking a kidney transplant because numerous studies have shown that patients who were noncompliant on dialysis are significantly more likely to lose their transplanted grafts (Brickman and Fins 1996; Douglas, et al., 1996; Schweizer, et al., 1990; Rovelli, et al., 1989). Moreover, noncompliance with transplant medications is a major cause of kidney rejection (Rovelli, et al., 1989; Schweizer, et al., 1990; Troppman, et al., 1995).

Traditionally, research investigators have used subjective and objective indices to measure dialysis patients' noncompliance. Subjective measures of noncompliant behavior are based on dialysis staff's observations, interactions with patients, and patients' self-report (Meers 1991). Objective measures typically include serum potassium (K), blood urea nitrogen (BUN), and interdialytic weight gain. However, there is no uniform measure of compliance used by all research investigators (Bame, et al., 1993; Kobrin, et al., 1991). Further, each of these parameters have been shown to be influenced by factors unrelated to compliance behaviors (Kobrin, et al., 1991). For instance, a study of nurses' ratings of dialysis patients' compliance behavior has shown their ratings to be based on their personal knowledge more than medical records (Edelman, et al., 1996). Personal knowledge included observations of patient behavior such as missed treatments, clinics, attitudes, and moods. The absence of consistent measures may explain why studies of compliance behavior yield conflicting results (Kobrin, et al., 1991; Wolcott, et al., 1986). That studies report inconsistent and contradictory findings on compliance behavior warrants caution when clinicians make treatment decisions incumbent upon it.

Studies have also found conflicting results that relate the prevalence of noncompliance among dialysis patients to their sociodemographic background (Bame, et al., 1993). A study of demographic characteristics associated with noncompliant behaviors among hemodialysis patients (n=1230) found that most (over 90%) patients were compliant with their diet regimen but only half were compliant with medication taking (50.2%) and fluid restriction regimens (49.5%) (Bame, et al., 1993). With regard to medication taking, younger patients were significantly less compliant, with the likelihood of compliance increasing 1.4 times for every 10 year increase in age ( $P=0.0000$ ). Low income<sup>128</sup> patients were 1.6 times less likely to comply with their medication regimen than medium income patients ( $P=0.0000$ ). Compliance with fluid restrictions was found to be significantly related to age, gender, “race,” and income of patients ( $P=0.0000$ ). Younger patients were less compliant, with the likelihood of compliance increasing 1.4 times for every 10 year increase in age. Male patients were two-thirds less likely to be compliant than females. While 51% of “black” patients were compliant with fluid restrictions, they were 1.4 times more likely to be compliant than “white” patients. Low income patients were 1.6 times less likely to comply with fluid restrictions than high income patients (Bame, et al., 1993).

Studies have also found that “blacks” and “Hispanics” are more likely to be noncompliant with dialysis and transplantation treatment regimens than “whites” (Douglas, et al., 1996; Schweizer, et al., 1996; Rovelli, et al., 1989). These studies attributed the higher incidence of noncompliance in “blacks” and “Hispanics” to the higher incidence of lower socioeconomic status in those groups. Clearly, these data indicate that the investigators should have compared classes and not “races.” Schweizer, et al., (1996) proposed that medical noncompliance may be

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<sup>128</sup> See Chapter 7.

due to the patients' confusion over taking a large number of medications. They also proposed that patients in the middle socioeconomic bracket who are not on welfare may experience difficulty obtaining medications if they lack insurance coverage for them. None of these studies, however, explained why sociodemographic patterns in noncompliance exist.

The concept of noncompliance is bound to a paternalistic conception of the physician-patient relationship (Holm 1993; Zola 1980:243). Most studies of noncompliance<sup>129</sup> assume that the patient-physician relationship is the key to understanding compliance behavior (Conrad 1985). There are two social scientific perspectives that explain why people alter their prescribed medical regimens: one finds the source of the problem to be in the patient-doctor relationship while the other proposes that patients' health beliefs inform their noncompliant behavior (Conrad 1985). The concept ultimately maintains a "medically-centered orientation" because it is healthcare providers who have defined patient noncompliance as a problem (Conrad 1985:30).<sup>130</sup> Healthcare professionals make several assumptions about noncompliant behavior, including: "1) all cases of noncompliance are problems in need of a solution, 2) the solution to the problem of noncompliance is compliance, 3) all instances of compliance are nonproblematical, and 4) the locus of the problem of noncompliance is the patient" (Coy 1989:826).

The notion of noncompliance implies that patients are accountable to the treatment decisions of physicians; those who fail to comply to the physician's wishes are deemed morally culpable (Holm 1993). The basis for moral culpability of noncompliance is the belief that there

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<sup>129</sup> Trostle (1988) found that there have been over 4000 scientific papers on noncompliance over the past two decades.

<sup>130</sup> Trostle (1988) contends that researchers who advocate using the term "non-adherence" instead of "noncompliance" implicitly maintain the ideology associated with "noncompliance" regarding its physician-centered approach to patient's "problematic" behavior.

are very few good reasons for engaging in noncompliant behavior (Holm 1993). Physicians assume that, like themselves, patients place health as the primary value in their lives, and thus should be compliant. However, other values can take precedence in the lives of patients, including, family, occupation, and religion, among others (Stein 1990:48; Coy 1989:828).

Medical anthropologist James Trostle has shown that the concept of noncompliance derives from a history of physicians explicitly seeking to exert control over their patients (Trostle 1988).<sup>131</sup> Trostle contends that medical noncompliance is an ideology that supports the authority of medical professionals. He explains that the research literature about compliance “is preeminently, although covertly, a literature about power and control” (1988:1299). Trostle defines ideology as:

“a system of shared beliefs that legitimize particular behavioral norms and values at the same time that they claim and appear to be based in empirical truths. Ideologies help to transform power (potential influence) into authority (legitimate control). Compliance is an ideology that transforms physicians’ theories about the proper behavior of patients into a series of research strategies, research results, and potentially coercive interventions that appear appropriate, and that reinforce physicians’ authority over health care” (Trostle 1988:1300).

As will be shown, in this study, the discourse on dialysis patients’ noncompliance can be seen as physician’s exertion of control over the access to transplantation.

One sociocultural value -- personal responsibility for health (Stein 1990:48; Gaines 1991; Reiser 1985; Wikler 1987) -- appears to account for many clinicians’ moral reactions to noncompliant patients (Stein 1990:110). The moral value of personal responsibility for one’s health most likely derives from the Northern or Protestant European conception of self, characterized as being “referential” (Gaines 1982), “ego-centric” (Shweder and Bourne 1982), and “individualistic” (Geertz 1973). Geertz describes the Western conception of self as:

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<sup>131</sup> The pervasiveness and normalization of the value of control over patients is best shown by physicians’ role in ‘patient management’ (Johnson 1993).

"a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment, and action organized into a distinctive whole and set contrastively both against other such wholes and against a social and natural background..." (1984:126).

Individualism in the US means the primacy of the individual in society; the self is identified with the conscious self, the seat of control (Gordon 1988). Maintaining responsibility for one's own health is arguably equivalent to maintaining self-control; for without doing so, one is considered "at fault" or deviant. The Western concept of self contrasts with that of the Mediterranean tradition (Gaines 1982) which is defined as "indexical" such that the self is defined through others, even including spirits.

The Northern European concept of self pervades much of biomedical theory and practice, namely in psychiatry (Gaines 1991, 1992a). For instance, those who are perceived as 'out of control' are deemed abnormal and labeled with psychiatric diseases. Deborah Gordon (1988) asserts that biomedicine has become the source of morality in US culture, by replacing moral idioms with medical ones, e.g., illness replaces sin. Marshall Becker (1986) expands upon the relation between morality and personal responsibility in biomedicine in *The Tyranny of Health Promotion*:

"the individual-responsibility approach has helped to establish 'health' as the New Morality by which character and moral worth are judged. 'Being ill' is redefined as 'being guilty.' The obese are stigmatized as 'letting themselves go.' Smokers 'have no will power.' Nonaerobics are 'lazy.'... The as-yet unproselytized are treated as sinners.... Health promotion, as currently practiced, fosters a dehumanizing self-concern which substitutes personal health goals for more important, humane, societal goals. It is a new religion, in which we worship ourselves, attribute good health to our devoutness, and view illness as just punishment for those who have not yet seen the Way -- a Weltanschauung that evokes Social Darwinism, the 'Me' generation, and the 1980s" (1986:19-20).

According to Foster and Anderson (1978), one of the functions of medical systems is sanctioning and supporting social and moral cultural norms. They write:

"Illness, seen as a penalty for disapproved conduct, is widespread in non-Western societies. Or, stated differently, the threat of illness as a consequence of socially unacceptable behavior plays a major role in many societies in maintaining the moral order" (1978:43, emphasis in original).



This is especially true when illness is attributed to sin, taboo violations, and wrongdoing. In the case of dialysis patients, noncompliance constitutes a form of wrongdoing according to healthcare professionals. Noncompliance coincides with Talcott Parson's (1958) view of illness as a form of deviance because the patient does not adhere to the sick role responsibilities of trying to get well (Conrad 1985).

A study of patients' adaptation to dialysis in the early days of dialysis therapy set the stage for the interrelationship of morality, social value, and medicine in the nexus of dialysis. The investigators reported that, "The expectations of important figures around him, the dialysis personnel in particular, were that he become independent, active, and productive" (Reichsman and Levy 1972:864). The investigators also believed that the main problem patients had in adapting to dialysis was their maintenance of "dependency" needs, which of course, precluded the possibility of "independent productivity." Linda Alexander (1976, 1980) called this problem the "double bind" (see Chapter 1). In describing the social construction of ESRD as a disease category, medical sociologist Alonzo Plough helps us to understand why dialysis professionals perceived dialysis patients' illness experience and behavior as deviant:

"the clinical construction of ESRD *blames the patient* for his pathological inability to 'cope' with the stress of dialysis and transplantation -- a version of Social Darwinism. The label 'psychosocial' is used as a catchall categorization for the crisis of experience for the patient, labeling the patient as deviant rather than questioning the disease construction. In this way, the technology can be considered successful; it is the patients who unfortunately but courageously fail" (Plough 1981:92, emphasis in original).

Behaviors that are considered 'inappropriate' e.g., noncompliance, are defined as syndromes, hence the dialysis staff's frustration with such deviance results in "powerful content for social control in ESRD care" (Plough 1981:93). The moral aspect of noncompliance is revealed through value-laden language about it: patients "admit" to, or are "accused" or "guilty" of engaging in noncompliant behaviors. Below we examine how this tradition in medicine of

physicians' moral animosity toward noncompliant patients affects nephrologists' referral practices.

### The influence of patients' noncompliance on nephrologists' referral practices

To understand how patients' noncompliant behavior affects nephrologists' referral practices, it is important to first consider how nephrologists in this study determine whether patients' noncompliant behavior really counts as noteworthy noncompliance. Since there is no established guideline, clinicians must make judgments about a patient's compliance according to their general senses of it regarding patients' attendance at dialysis treatments and clinic visits, and taking medications. Dialysis professionals generally acknowledge that, in the words of Dr. Nicola, "If patients skip a treatment or office visit here and there, that's only human." However, clinicians reported that *repeatedly* missing treatments or appointments over many months constitutes noncompliance. Missing more than two dialysis treatments a month is considered a "worrisome" pattern, said Dr. Young. In addition, Dr. Testa felt that repetitive noncompliant behavior among patients who have had "a good six months of initiation on dialysis" is of concern because they have already learned how to take 'proper' care of themselves.

After determining that a patient is noncompliant, nephrologists must decide whether to refer them to the transplant center if they are medically eligible for it. All nephrologists reported that patients' noncompliant behavior does not prevent them from referring patients. However, noncompliant behavior may be factored into their evaluations after accounting for medical eligibility. Thus four nephrologists said that they inform the transplant center of referred patients' noncompliant behavior so that transplant professionals can take that factor into consideration in their transplant evaluations. As Dr. Testa noted, "Everybody will experiment a little bit but repetitive major noncompliance... I'll still refer them but I refer them with a note

saying major noncompliance.” The reason for informing transplant centers of patients’ noncompliant behavior is because “they are at serious risk of not taking their [transplant] medications,” noted Dr. Nicola.

The assumption underlying nephrologists’ concerns is that noncompliant dialysis patients will also be noncompliant with their kidney transplant resulting in kidney rejection. This assumption is based on the empirical studies of noncompliance as well as clinicians’ experiences managing noncompliant patients over time. As Dr. Gilmore made clear, “Right, you don’t want to waste the kidney, because the patient’s not going to take their medicine and they’re just going to reject it.” In addition, it is apparent that nephrologists find it important for transplant professionals to take into consideration patients’ noncompliance when evaluating potential transplant candidates. Here we see physicians engage in subtle practices that intend to preserve scarce kidneys from possible waste.

A not so subtle physician practice observed in this study contradicts nephrologists’ claim that patients’ noncompliance has no impact on their referral practices. A review of the largest dialysis center’s list of patients (n=395) and their transplant eligibility status on their LTCPs revealed that there are several patients, under the care of three different nephrologists, who are considered medically ineligible due to noncompliance. Recall that determinations of eligibility for transplantation are made by nephrologists. Dr. Julian gave this status to two of his patients because they were blatantly noncompliant by never attending office visits (one had not attended in four years). Dr. Julian said that he had never referred the patients to the transplant center, and had determined the patients’ status himself. Thus, the transplant center had not made the assessment of the patient’s ineligibility for a transplant. When one of the two patients recently

expressed interest in a transplant, Dr. Julian told the patient that he would need to demonstrate a significant period of compliance before referring him to the transplant center.

The decision by Dr. Julian, and probably the other two nephrologists, to wait to refer patients to the transplant center until they have become compliant is an important factor that affects patients' access to transplantation. Although there were only a handful of patients who were found to be in this liminal status at one dialysis center, it is possible that other patients at other centers are likewise prevented access to transplantation. By this token, the actions of Dr. Julian and the other nephrologists represent the role of a gatekeeper. Yet Dr. Julian's practice makes sense considering the fact that had he referred such patients to the transplant center, they would have likely been rejected due to noncompliance.<sup>132</sup> Dr. Julian's practice may be seen as appropriate since he had informed the patient of the reason for the ineligible transplant status and what is necessary to become referred. Dr. Julian might have even used the possibility of eventual referral as a way to encourage compliance in the patient.

Most nephrologists and other dialysis and transplant professionals seemed to express moral animosity toward noncompliant patients even though they refer them to the transplant center. Specifically, two nephrologists commented that they hope noncompliant dialysis patients would be given less priority than compliant patients in obtaining a transplant. For example, Dr. Testa stated, "I would definitely think that a noncompliant patient would hopefully be considered at a lower level than a compliant patient. And I sincerely mean that." According to Dr. Avi, patients who are noncompliant will say they forgot to take medicines or try to find excuses, so "if a patient doesn't care about being compliant, why should I care?" In addition, two other

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<sup>132</sup> I thank nephrologist, Ash Sehgal for these helpful insights into this practice. How transplant professionals evaluate noncompliant patients will be examined in Chapter 9. Even one patient in this study (Allison) reported that she had previously been removed from the transplant list for noncompliance.

nephrologists (Drs. Gilmore and Olson) indicated that they would worry and be skeptical about giving a second transplant to a patient who was noncompliant with the first one, but they let the transplant team deal with it. As these statements and practices show, morality creeps its way into the culture of medicine. Nephrologists are aware of their own negative feelings about the prospect of noncompliant patients receiving a kidney transplant.

The moral animosity on the part of nephrologists toward noncompliant patients may be related to the fact that eleven of twelve nephrologists were European American and likely adhered to the Northern European concept of self defined earlier in the chapter. Their tension regarding the importance of compliance behavior may stem from differences between nephrologists and patients' concept of self with regard to personal responsibility for one's own health. Thus, those patients who are less likely to share healthcare professionals' concept of self, e.g., African Americans, might be labeled as noncompliant more often than others (Waxler 1980). Or, the moral animosity may be a result of racism.

A minority of nephrologists ( $n=3$ ) in this study were more understanding of noncompliant patients. This exception is not surprising given that biomedical practitioners are not homogeneous in attitude and practice (Gaines 1985b). Two of these nephrologists disliked the concept of noncompliance because of its connotations of power differentials between doctors and patients, and tended not to rely on evaluations of compliance behavior in their assessments of patient suitability for transplantation. Instead, they preferred to take into consideration the fact that broader life situations can influence people's health-related (and noncompliant) behavior, often for unavoidable reasons. Dr. Easton explained her approach to so-called noncompliant patients in her practice:

"Well, I think if a person can understand and is interested in their care, even if they don't actually do every single thing I tell them to do, I don't feel that that should count against them as far as putting them on the transplant list.

Because there's a lot of different things that come in, like for instance, if people don't come to treatments all the time, is it a transportation issue? Is it just because they don't want to come? And I think that the regimen, even though I'm not a transplant physician, things that will cause people to be noncompliant on dialysis may not cause them to be noncompliant on transplant. So I try to think through how the patient is likely to react in a different situation not necessarily how were they're reacting in their particular situation. Because the demands of being a transplant patient (and there are demands) are different from the demands of being say, a hemo patient from the demands of being a PD patient. So it's very individualistic. I wouldn't rule out a person who is so-called noncompliant."

Dr. Alland, another nephrologist who was more accepting of noncompliant behavior, sought to eliminate the power discourse inherent in the term by referring to the behavior as 'nonadherence.' In his view, there are two schools of thought about nonadherence behavior based on generational differences between physicians: "I think there's a school of thought among ... many of us older types in dialysis, that the main value of dialysis is to allow the patient to eat. And that if you allow the patient to eat a good sound diet then you clean up the mess with dialysis." The younger generation of nephrologists, he contended, tend "to read the textbooks and treat laboratory tests a little bit more assiduously than they probably deserve." The third nephrologist, Dr. Varga, commented on the need to understand the difference between compliance due to: "a willful lack of compliance," "no access to the health care system," and "access but no money to buy resources."

Noncompliance, as a physician-derived concept, is problematic for several reasons. Trostle clearly defines the nature of the problem as when healthcare providers "den[y] the legitimacy of behaviors that differ from the clinical prescription. When physicians label their patients 'noncompliant' they often distance themselves from their patients' actions, judging and labeling rather than analyzing and understanding" (Trostle 1988:1305). The crux of the issue is that an inaccurate judgment can negatively effect patients. In other words, nephrologists and other dialysis clinicians may wrongfully label patients "noncompliant" when patients have either *involuntarily* or *voluntarily* acted in ways which really do not constitute noncompliance, though

clinicians may perceive it as such.<sup>133</sup> Consequently, the misjudgment of patients can hinder or make more difficult their access to transplantation. Let us first consider what is meant by involuntary noncompliance.

### *Involuntary noncompliance*

Involuntary noncompliance means not being able to comply with the doctor's orders because of constraints beyond a person's control. Involuntary noncompliance makes sense within the physician-oriented conception of noncompliance. Two examples of involuntary noncompliance are financial and transportation problems. Financial difficulties may hinder patients from purchasing necessary foods for their specialized renal diets. One patient, Douglas, worried about not having enough money for food after the DHHS stopped providing him with \$137 per month in food stamps. Many patients are required to eat protein-rich but low-fat foods, particularly meat. But lean meat is relatively expensive. According to Dr. Ingel,

"Many people will *admit* that by the end of the month when their check runs out, they don't have money and they say well, 'you drew the lab tests at the wrong time of the month.' I've had patients tell me that 'I eat better early in the month, than when the money was getting tight, and I wasn't eating as well'" (emphasis added).

Vegetarians especially find the requirement to eat meat unappealing, as three of twenty-one patients noted (all females, two European Americans, one Lebanese). Four of twenty-one patients reported that they were unable to take the prescribed dosage of medicines because they could not afford them before their Medicare coverage began (three males, all European Americans). Sofia reported that she did not inform her doctor about this because she "felt ashamed."

Another example pertains to patients who are medically unable to walk or drive and are provided transportation to dialysis centers by taxi or ambulette services funded by Medicaid.

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<sup>133</sup> The terms "voluntary noncompliance," "involuntary noncompliance," and "compliance anomalies" are all etic renditions of observed, documented, and reported phenomena.

Four patients claimed that their cab drivers sometimes forgot to pick them up or brought them to the dialysis center late (three African Americans). It is proposed here that impoverished patients may be at greater 'risk' of being unable to accommodate their dietary, medical, and treatment regimens.

### *Compliance anomalies*

In contrast to those who try to follow clinical recommendations but cannot for reasons beyond their control, there are some dialysis patients who report conscientiously following all dietary and treatment recommendations but are still mistakenly perceived as noncompliant. The question we must now ask is, Can laboratory tests reflect noncompliant behavior when patients have actually been compliant? Both nephrologists (n=3 of 4) and dialysis patients in this study<sup>134</sup> (n=2 of 19) (Richard, Irving) and on the Internet (n=4) asserted that this discrepancy or anomaly did and/or could happen. Four of the six patients were male. Five of the six patients related that they had been compliant but were thought not to have been by their nurses. For instance, Richard diligently took his prescribed amount of coumadin (a blood thinner) even though he has a history of fluctuating blood pressure levels. His dialysis nurse often called him at home and "accused" him of not taking his coumadin because his levels were unstable. Richard recounted his reaction to the nurse, "I'm telling her I'm taking it, trust me!" He knew that he was taking a large amount of coumadin since he developed blood blisters on his legs. But the nurse, unaware of his history, disbelieved him. Richard related his frustration with the lack of trust by noting, "She looks at the numbers and not at me." Other Internet patients' experiences with this are as follows.

Stephanie: "I was 'accused' of non-compliance by the nurse handling my case when I was on PD. My calcium was high, she continually insisted I must be eating foods too rich in calcium when I knew I definitely was not doing so. In the end it has turned out that I have lost a considerable amount of bone mass. Presumably the high blood calcium levels were due to the calcium being drawn from my bones (and not due to any dietary indiscretions on my part). I

<sup>134</sup> Only two patients from the first group and all (n=19) patients from the second group were asked about their compliance behavior.



found it extremely frustrating trying to convince this nurse that I was following my diet. She would insist I 'must' be eating dairy foods, sardine bones, etc."<sup>135</sup>

Jennifer: "As a matter of fact, all the PD nurses were in an uproar, concerning my 'noncompliance' on taking EPO. They had (yes- the head nurse controls the dose - NOT the MD!) prescribed 9500 units 2x/week, and I would only use 7500. The higher dose was causing stinging and bruising. They said it would be viewed as noncompliant, and may interfere with getting a transplant. I asked to have the script lowered. 'The doctor would never approve of that,' said she. 'Let's ask him,' said I. As it turns out, as low as my iron stores were, the higher dose of EPO would have been detrimental; and the MD made them change the orders."<sup>136</sup>

One of the Dialysis Listserv members related such patient experiences to financial incentives in health care:

"Unfortunately, this pattern of victimization/infantilization/invalidization is par for the course at most dialysis clinics, especially at the big-profit companies who dominate the industry. Our rights are theoretically protected by the 'Patients' Rights and Responsibilities,' although that document is most often treated as just so much extra wallpaper."<sup>137</sup>

There was a tone in the Dialysis Listserv discussions about mistaken compliance, that patients have become skeptical of healthcare professionals because of the lack of understanding that is perhaps engendered by financial incentives in the provision of health care. In contrast, two patients asserted that fluctuations in blood chemistry reports are usually due to noncompliance though patients may be unaware or deny that they engage in noncompliant behavior.<sup>138</sup>

The three nephrologists who acknowledged that the above situation could occur explained that it is usually the physician who is at *fault*. According to Dr. Ingel,

"If someone is following their diet and taking their medicines but their blood pressure is too high, then the physician either hasn't adjusted their dry weight on dialysis or hasn't adjusted their medicines. Or, if their phosphorous is too high, then we have to increase their phosphate binders appropriately. So, by definition, if the patient's not at fault, the physician is."

Dr. Alland likewise attributed this poorly understood phenomenon to physicians who write "ridiculous prescriptions." For instance, physicians may prescribe four phoslo (phosphorous)

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<sup>135</sup> "Compliance", private e-mail message to Elisa Gordon, 27 March 1998.

<sup>136</sup> "Compliance", private e-mail message to Elisa Gordon, 27 March 1998.

<sup>137</sup> Frank, "Dialysis Mind (was Going Nuts!!!)", in <dialysis@wugate.wustl.edu>, 27 July 1997.

<sup>138</sup> Danielle; "Compliance", private e-mail message to Elisa Gordon, 27 March 1998.

instead of two phoslo pills at every meal. Phoslo pills are known to be difficult to take because of their giant size thus leading to noncompliance among some patients. These discrepancies in interpretations and causations of noncompliant behavior suggest that patients may be wrongly 'accused' of noncompliant behavior.

*Voluntary noncompliance or "The Patient-Oriented Perspective"*

Noncompliance can be examined in an entirely different light -- from a patient's perspective. The patient-centered perspective "sees patients as active agents in their treatment rather than as 'passive and obedient recipients of medical instructions'" (Conrad 1985:30). In other words, "If it is ultimately the patient who has to decide, after being duly informed and advised, then he cannot be non-compliant" (Holm 1993:108). Noncompliance with the doctor's orders for reasons that appear "valid when analyzed dispassionately" has been denoted "intelligent noncompliance" (Weintraub 1976:40-41). Patients who engage in intelligent noncompliance can be seen as expressing their autonomy and as making a reasoned decision.

As autonomous decision making, patients may engage in 'noncompliance' because it can express their disagreement or dissatisfaction with clinical advice (Trostle 1988). Healthcare professionals can express their respect for individual dignity by recognizing noncompliant behavior as an expression of a patient's legitimate autonomous decision (Coy 1989). Patients may engage in 'noncompliance' because they are making a reasoned decision (Donovan and Blake 1992; Trostle 1988; Conrad 1985). For instance, the practice of altering medicine-taking because of the problematic side-effects has been found among epileptic patients (Conrad 1985) and rheumatology patients (Donovan and Blake 1992). In both instances, there were rational reasons that patients altered their medicine-taking.

Among epileptics, patients' decisions to alter their medications had little to do with the impact of physicians, rather it was an issue of regulation of control of self (Conrad 1985). Conrad found that 34 of 80 respondents (42%) self-regulated their medications for various reasons, including: a) the medicine is seen as ineffective or the side-effects are too troublesome, b) to better manage their everyday lives, e.g., to stay more alert or avoid seizures in high stress situations, and c) to downplay the stigma of being an epileptic patient.

A study of 'noncompliant' behavior among 25 of 54 (46%) patients with inflammatory arthropathy found that such behavior constituted a form of reasoned decision making on the part of patients rather than a form of deviance (Donovan and Blake 1992). These patients carried out their own cost-benefit analysis for the treatments they were offered according to their lay beliefs and information available to them. For instance, many patients were reluctant to take their medicines because of the belief that reliance on drugs was a sign of weakness. They therefore experimented with the dosages and timing of their medications to evaluate whether their benefits justified the side-effects.

Similarly, some dialysis patients (16 of 21) reported that they do not always heed their nephrologist's or dietitian's clinical recommendations for various reasons. Some (12 of 21) perceived little benefit in their medication when it caused pain or discomfort and thus took medicines at a different time than prescribed (n=11) or in different amounts than prescribed (n=4). Others (4 of 21; plus others not included in this study) found that changing their eating habits was too difficult because they were raised within a certain tradition, e.g., soul food (three females, two African Americans). Still others believed that they were already receiving 'adequate' care without having to make any medical or dietary changes. Moreover, a head nurse of a dialysis center explained that many patients do not go to their clinic visits because of rational

considerations such as: a) time: patients already spend much time in the hospital or dialysis center and do not want to spend any more time there, and b) convenience: patients feel that they are already being seen by their nephrologists during weekly rounds.

As these studies and data show there are good reasons for so-called ‘noncompliance.’ Perhaps the most poignant issue is that physicians “often prescribe ‘standard’ treatments from the book without sufficient regard to the patient’s specific situation, and without sufficient discussion” (Holm 1993:109). While physicians are more knowledgeable about a disease process in general, patients are more knowledgeable about their own disease and how it is manifested within them (Holm 1993:109). Given an understanding of the range of misinterpretations of noncompliance, we can move on to discuss the implications of being ‘accused’ of noncompliance and the ethical concern about passing moral and medical judgment on patients based on their health-related behavior.

As the above discussion reveals, many factors contribute to the inaccurate measurement of noncompliance behavior. Let us briefly review these factors. First, objective measures of compliance/noncompliance have yielded contradictory results. Second, measures of noncompliance also rely on personal and subjective measures which are problematic because they encode morally-based judgments. Third, as shown by patients’ experiences, clinicians can misinterpret compliant behavior. Fourth, patients’ autonomous and rational decisions are interpreted by clinicians as deviance.

#### *Implications of noncompliance*

Although many objective measures of compliance behavior generate accurate assessments, the fact that fallacious assessments of noncompliant behavior occur<sup>139</sup> is cause for

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<sup>139</sup> As of yet, no studies have documented this phenomenon or its rate of occurrence.

concern. The misperception or misinterpretation of noncompliant behavior on the part of dialysis and transplant professionals can, in part, unnecessarily tarnish a patients' medical reputation. Since nephrologists document noncompliant behavior in their referral letters to the transplant center, misinterpreted patients may unjustifiably be held back from obtaining a transplant. Yet this raises the larger ethical question of whether temporarily hindering (so-called) noncompliant patients from obtaining a transplant is warranted. According to physician-lawyer-bioethicist, David Orentlicher (1991), health professionals may be tempted to deny treatment, e.g., dialysis or transplantation, to noncompliant patients particularly if they are at 'fault' or responsible for their behavior. However, Orentlicher points out that "physicians should not demand that patients waive any of their fundamental rights as a condition of treatment" (1991:1581), meaning that patients should not be required to waive their right to refuse treatment in order to receive medical care.

Patients may accommodate dialysis in their lives in ways that are more comfortable to them and livable than established by their treatment and medical regimens. It is likely that patients' definitions of comfort and their manners of accommodation are shaped by ethnic or cultural patterns and socioeconomic limitations. Of the eight nephrologists asked, over half reported that they have noticed patterns in noncompliant behavior among people of different ages, genders, ethnic, and economic backgrounds but noted that these sociodemographic variables were interrelated. These patterns will be analyzed in greater detail below.

Some nephrologists (n=3 of 7) and other transplant professionals (n=4 of 6) believed that age is a factor influencing compliance behavior. In their experience, they found that younger patients tend to be less compliant than older patients. An explanation for this trend was offered by Dr. Olson:

"I think it's probably because in my estimation, younger patients accept going on dialysis less well. They're active, they're at a point in their lives when something happens and all of a sudden they're stuck with this dialysis treatment. Whereas older people who've lived longer, who seem to be much more accepting I think in a lot of cases, it's not always the case."

Three nephrologists and two transplant professionals believed that ethnicity played a role in compliance behavior. Specifically, they found that African American patients were less compliant than European American patients. Two medical directors of dialysis units (Drs. Varga and Gilmore), composed of different patient populations, related that the rate of noncompliance varied according to the location and ethnic composition of the units. In the suburban, primarily European American dialysis unit, the noncompliance rate was less than 1%, while at the urban, poor, primarily African American dialysis unit, the noncompliance rate was approximately 10%. Dr. Varga attributed this ethnic difference to socioeconomic differences in the following way:

"At the dialysis unit at [suburban] we very rarely had to supply transportation to get somebody back and forth to the dialysis unit because most people, if they didn't drive, they had a family member who drove. At the unit across the street [urban], transportation is one of our major problems because very few people have their own car who drive themselves or have a family member who has a car who could drive them. They have to depend on public transportation. Well, sometimes the taxi doesn't show up. There's a contract between the taxi company and the county for taking the poorest of the people, the Medicaid patients. Well, that's for a certain amount, say it's \$7 bucks or \$8 bucks a transfer. If this cab can get a fare that goes out to the airport where they're going to make \$20 bucks, they just don't show up to pick up the person who's relying on that cab to come here."

The urban dialysis center Dr. Varga referred to was primarily African American while the suburban center was comprised of primarily European American patients. Dr. Riley similarly noted that noncompliant patients tend to have less education, those with less education tend to be poor and of minority backgrounds. Two nephrologists (Dr. Lock, Dr. Nicola) also reported that noncompliant behavior tended to occur among patients with less education. According to Dr. Nicola, more educated and more wealthy people are more concerned about their health, and, as he put it, are "hypervigilant" about it. He illustrated this difference in SES and health behavior by relating to population differences by city: "Out in [wealthy suburbs], people are healthy but

will come in asking for a cholesterol test. But near American University, people don't seem to care about their health."

Two nephrologists and one transplant professional related ethnicity to age in compliance behavior. They reported that "young 'black' males" tend to be more noncompliant than other ethnic/age groups. To provide insight into Dr. Gilmore's understanding of this issue, the extensive conversation is presented verbatim below:

- Dr. G: Young black males tend to be most noncompliant and that's a pattern that's been reinforced in the literature.  
EG: Why do you suppose that is?  
Dr. G: Because there is a feeling of invulnerability. They think they're immortal. No matter how noncompliant they are, they're never going to get sick or die.  
EG: Is there a cultural thing?  
Dr. G: I don't know if it's cultural, but, you know how, then again I hate the stereotype but there's a certain kind of overcompensation or confidence on the part of 'black' males, you know, the swagger if you will. And I think it's also reflected in this concept that 'I'm invincible, and nothing can hurt me, and therefore I don't need to take my medicines because I don't have to fear that there are going to be adverse consequences.'  
EG: I wonder what generates that kind of feeling?  
Dr. G: You mean in terms of cultural?  
EG: Yeah, I don't know enough about it.  
Dr. G: I can't tell you, but that's a pattern that I see, and when I look at my treatment records of patients who are out in the dialysis community, you know I go through their records every month and I can see the number of treatments that they skipped, and I can tell you that by far and away, I'm sure it's highly statistically significant that the most skips are among 'black' males, young 'black' males.  
EG: Is there a lot of literature on this?  
MD: There is literature on it. But almost all the other nephrologists will agree with me. They'll say, 'Yeah, this is a pattern, it's important.' Interestingly enough, there may be something to their concept of invulnerability because despite their poor compliance, their mortality is the lowest. [he laughs because of the irony of it all!]  
EG: I've heard how African Americans tend to do really well on dialysis.  
Dr. G: Right, African Americans are better than 'whites,' and males are better than females, so coupling the two, it turns out that 'black' males do best. So maybe they are right, they are invulnerable. [We laugh].  
EG: Is there any medical, genetic, any kind of explanation you've heard about as far as those two trends?  
Dr. G: Well, prognosis in dialysis patients in terms of mortality tends to correlate highly with nutritional status and muscle mass. People with the highest creatinines and highest albumins tend to do the best and live the longest. As it turns out, 'black' males score best in both those counts. They tend to be very well nourished, and they tend to have a high muscle mass.

Dr. Gilmore substantiated his perception of patterns of noncompliance by reference to the literature. However, the literature on noncompliance cited above is inconsistent in the relationship between noncompliance and ethnicity. Other nephrologists supported the claims of the physician involved in the discussion above. One believed that young "black" men with high

blood pressure feel well and normal so they do not take their medications. As young men, they feel indestructible. There is evidence that African Americans wait to seek health care until they are very sick (Gaines 1988/1989; Reed, et al., 1993). According to an African American bioethicist, “Since there is a strong emphasis on immediate response and relief of pain, African-Americans are unlikely to focus on or be interested in wellness and prevention, especially those in the lower socioeconomic groups” (Murray 1992:40).

The basis of young African American males’ feeling invulnerable may be due several factors. First, it may be related to a fatalistic worldview (Turner and Kiecolt 1984; Venkatesh 1994) whereby the prospects of living a long life seem dismal having grown up in an inner-city environment where many African American males die young due to violence, poverty, illness, and poor access to health care.<sup>140</sup> Male African Americans may approach their health in a way in which they would rather live a full life than one limited by the restrictions imposed by dialysis, believing that they will die young regardless. Second, young “black” males may miss dialysis because of their reasoning about the consequences or risks involved in doing so. Notably, because they do not *experience* the kinds of problems assumed to befall all dialysis patients who miss dialysis, young “black” males reason that missing treatment is not harmful or risky to them. As initially described in Chapter 7, we again see a clear example of patients who are “natural empiricists” (Gaines 1993). And again it appears that biomedical and lay conceptions of risk differ due to differences in the processes of reasoning.

The trend of African Americans being noncompliant with taking anti-hypertensive drugs and with undergoing treatment for alcohol has been explained in terms of explanatory models

<sup>140</sup> Based on the National Center for Health Statistics’ National Health Interview Survey, the total US population visited physicians an average of 5.3 times per year between 1985 and 1987, however, “whites” had 17% more visits per person than “blacks” (Reed, et al., 1993:95). In addition, homicide is the most frequent cause of death for “black” men between the ages of 15 and 34, which is a rate seven times greater than that of Whites (Reed, et al., 1993:134).



and folk theories (Heurtin-Roberts 1993; Snow 1974, 1991; Gaines 1985a:188-189). We can argue that some of the same folk theories which encompass a concept of self may explain some of the observed differences by ethnicity in compliance with dialysis. In contrast to the Northern European concept of self discussed earlier, some African Americans maintain a conception of persons, quite like that of the Mediterranean (Gaines 1982), as immutable from birth. Thus, while Northern Europeans would consider a problem as a changeable component within a person, some African Americans consider a problem as a “natural” part of a person whereby a person is only “being him-(or her)self” (Gaines 1985a). In addition, African Americans’ lack of compliance with drug rehabilitation and other practices can be attributed to folk theories which assume that an external agency, e.g., racism, oppression, voodoo, rather than oneself, is responsible for causing a problem (Gaines 1985a; Snow 1974).

Given these sociocultural and economic patterns, the question we are left asking is, If some ethnic groups or socioeconomic strata, e.g., African Americans, tend to be more noncompliant than others, then they are at even greater risk<sup>141</sup> of not getting access to transplantation. Is that fair?

The discussion and examples provided by patients above raise several broader concerns about the culturally constructed practice of medicine in the US. These concerns specifically pertain to medical power and control in the context of contested medical knowledge. How healthcare professionals deal with patients who appear noncompliant because they take charge of their own health by adjusting clinical instructions raises another important issue. On the one hand, dialysis professionals encourage and applaud patients who actively take care of themselves in a way consistent with the goals espoused by scientific medicine, e.g., independence, as in the

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<sup>141</sup> Further study of dialysis patients’ conceptions of the clinical and social risks of noncompliance with dialysis treatment would provide greater insight into the differences between lay and professional forms of reasoning.

case of in-center hemodialysis patients inserting their own needles and monitoring their own dialysis machines (Alexander 1976, 1980). On the other hand, patients who independently care for themselves but in a manner contrary to an established medical regimen are perceived by healthcare professionals as sick (Balshem 1997) or as problems (e.g., noncompliant) because such patients undermine the power structure inherently mediating clinical medical practice (Taussig 1980). Those who do not follow medical directions are seen as irresponsible; the culture of medicine, in its medicalization practices, uses the label ‘illness’ to attribute “diminished responsibility” to various phenomena (Zola 1972:491).

This brings us to the issues of contested knowledge and the question of authority to define and treat sickness<sup>142</sup> experience. Consider the two groups of noncompliant patients discussed above: the anomalous compliant patients and the voluntary noncompliers. Both groups of patients exhibit knowledge of their body grounded in practical experience with having ESRD. In other words, through daily living with ESRD, both groups of patients have learned how to interpret the meaning of their body’s symptomatology and laboratory tests. Yet these interpretations are contested by nurses and physicians who are aligned with a scientific model of medicine and perceive deviation from this model as cause for alarm. In other words, dialysis professionals perceive patients (like Stephanie and Jennifer above) who experience a set of bodily conditions that conflict with medical interpretations of their laboratory tests as the source of the anomalous problems. Studies show that health professionals rely heavily on laboratory tests to relieve anxiety about clinical uncertainty (McCombie 1989:847). Healthcare professionals deal with patients’ anomalous bodily conditions by denying or disregarding patients’ interpretations of the cause and imposing biomedical interpretations. In the process of

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<sup>142</sup> I use the term “sickness” to include both illness and disease based on the work by A. Young (1982).

doing this, healthcare professionals dismiss patients' suffering and reinforce a power structure of medicine. Biomedical interpretations trump patients' interpretations of anomaly in bodily functioning. In the cases of Stephanie and Jennifer, nurses contested the patients' knowledge of renal disease symptomatology, which escalated to the point of requiring the ultimate authority in medicine -- the physician -- to acknowledge the problem. The physician's revised drug prescription served as a recognition of the patient's interpretation of anomalous events yet it represented medicine's authority to legitimize illness and responses to it.

The issue of contested medical knowledge has arisen in other research studies (Taussig 1980; Balshem 1997). Taussig's analysis of the "disputes of power" pertains to patients' loss of autonomy to medical professionals. The core of the dispute is identifying who has the power to define sickness and to define appropriate responses to it. Taussig writes:

"The clinical situation becomes a combat zone of disputes over power and over definitions of illness and degrees of incapacity. The critical issue centers on the evaluation of incapacity and of feelings such as pain, and following that on the treatment necessary. Here is where the professionals deprive the patients of their sense of certainty and security concerning their own self-judgment" (1980:9).

In another context, for example, such a dispute of power occurred when health educators sought to teach a working-class community about ways of reducing their risk of cancer, in The Project Can-Do (Balshem 1997). The health educator, assuming the legitimacy of medical scientist, "tacitly claims the power to define public health issues and to assign value to different lifestyles" (1997:24). The community's resistance to the educator's scientific authority was manifested in their lack of faith in medical science's etiological notions of cancer. Instead, they believed that fate was one of many etiological factors of cancer, even more powerful than lifestyle. Community members expressed frustration at science's view that everyone is vulnerable to cancer because of its environmental etiology, and perceived making lifestyle changes to lower cancer risk as useless. The community drew upon personal stories of people

known in the past who engaged in what health educators believed to be high risk behaviors (e.g., smoking, high fat diets) yet never became afflicted with cancer, to prove that the scientific model was wrong. This “defiant ancestor” story embodied community ways of life, self-reliance, and defiance of scientific medical advice. The community felt excluded from having the power to define clinical reality because they realized that the educators did not view their interpretations of experience as valid, and thus perceived the community as sick. Yet the community refused to perceive themselves as sick, and charged the scientific authority with hubris (1997:37).

Like the parties involved in Balslem’s ethnographic account, there appears to be a power struggle between dialysis patients who live in ways that accommodate their needs and interpret clinical tests according to their grounded experiences, and dialysis clinicians who present scientific interpretations of renal tests as authoritative. At base is a struggle between theory and practical knowledge. The examples from dialysis patients reflect the need for health professionals to understand how patients deal with treatment in their everyday lives (Zola 1980) before labeling them with a pejorative term such as noncompliance that has significant consequences on obtaining available treatment options.

#### Discourse on preemptive transplantation

Nephrologists’ decision about whether to refer patients to the transplant center may be influenced by a discourse among them about the advantages and disadvantages of transplanting patients before they even begin dialysis, known as preemptive transplantation. One study compared 85 cases of preemptive transplants to a control group of demographically and medically matched patients who had been on dialysis at least six months prior to transplantation, to determine whether there were medical advantages to preemptive transplantation (Katz, et al., 1991). The study found that while there was no difference in one and two year patient and graft

survival rates between the two groups, significantly more preemptive patients were vocationally rehabilitated after transplantation ( $p < 0.01$ ). However, significantly more preemptive patients were noncompliant with their kidneys resulting in rejection ( $p < 0.001$ ). The research investigators explained that “the lack of exposure to the rigors of participation in a dialysis regimen and in chronic medical follow-up engenders a perceived independence from the system with increased noncompliance” (Katz, et al., 1991:354). Because of this trend, the transplant center sponsoring that study maintains a policy to not retransplant preemptive patients who have lost their graft due to noncompliance without patients undergoing a six month dialysis period.

The dialysis and transplant professionals in this study reported similar experiences to the study noted above with patients they had preemptively transplanted. But there are additional dynamics to this issue that can be teased out from comments made by transplant professionals. Most nephrologists asserted that transplanting patients before they begin dialysis is the ideal situation. Patients with slow progressive renal disease are encouraged to consider and get listed for transplantation as early as possible to bypass the need for dialysis as soon as their kidneys reach end-stage. One advantage of making transplantation preemptive to dialysis is that patients can avoid the preparatory surgeries necessary for dialysis. Dr. Olson explained another advantage in terms of the negative consequences of reversing the order of treatment:

“One of the impediments to getting patients on the list after they’ve been on dialysis for a while is that I think we’ve probably lost a cohort of patients over there who are unwilling to consider it because all of the patients who have gotten transplants that they’re familiar with are back on dialysis and coming back to tell them their *horror stories*. So it’s kind of an ascertainment bias— they see all the failed transplants and so that’s why I think it’s really key to get these people early on, thinking about it, get them involved. Occasionally we’ve been successful in getting somebody a kidney before they get on dialysis but it doesn’t happen nearly as often as we’d like to see” (emphasis in original).<sup>143</sup>

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<sup>143</sup> The role of the social context of dialysis treatment on patients’ decision making has been discussed further in Chapter 7.

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On the other hand, nephrologists and other transplant professionals have indicated that there is a disadvantage to transplanting patients before they experience dialysis, similar to the findings reported by Katz, et al., (1991). A transplant coordinator, Lorna, explained the disadvantages within an historical framework. In the 1970s, she said, when patients received a transplant, their health generally improved drastically and immediately. Because of the significant change in health status patients experienced with a transplant compared to dialysis, they were very committed to taking their transplant medications to prevent rejection. In the 1990s, however, patients generally experience less of a drastic change in health status and are more likely to be less compliant with their medications, thereby threatening the survival of the scarce resource.

The difference between these two attitudes represented by the two decades is due to technological advances, specifically, the advent of erythropoietin<sup>144</sup> and the improvement in dialysis efficiency in more recent years. Dialysis performance has also been improved such that patients do better, and live longer on dialysis now than they did twenty years ago. In the 1970s, nephrologists began dialyzing patients after a period of time of uremia, meaning that patients were much sicker (Reichsman and Levy 1972; Stewart 1983:624). At that time, without these advances, patients' health status on dialysis was much poorer than it is today; patients who received a transplant felt a greater improvement in health and took greater precautions (read: compliance) to safeguard their kidney from potential rejection than patients do in the 1990s. Consequently, patients in the 1990s are more likely to feel pretty good on dialysis and therefore are more willing to take risks with altering their treatment regimen.

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<sup>144</sup> Erythropoietin is a synthetic hormone that stimulates the growth of red blood cells. This medication is routinely given to patients on dialysis because their kidneys no longer produce the hormone that performed the same function, and it improves health by providing greater energy and strength.

The disadvantage of preemptive transplantation was explained in terms of “appreciation.” Such patients do not “appreciate” a transplant as much as patients who have been on dialysis because they lack the experiential basis from which to compare the two treatment modalities. Consequently, patients who get a transplant before dialysis are likely to complain about the transplant, especially if they experience adverse side-effects of immunosuppressant drugs. Patients in this category have even demanded that the transplant team “take it out of me!” because the kidney graft and its maintenance were too upsetting to deal with.

The transplant team expressed the view (though not all agreed with it) that patients who have been on dialysis for one year would be more appreciative and complain less about their transplant and the effect of it on their life and therefore would more likely “take good care of their kidney.”<sup>145</sup> Both patients and transplant professionals experience problems with preemptive transplantation; the disadvantage presented by this situation is not medical but psychosocial because patients present a nuisance for the transplant team which must manage their care. While transplant professionals might prefer that patients experience dialysis before transplantation for these reasons, there are serious legal repercussions for not referring eligible patients for transplantation. As previously discussed, nephrologists are mandated by HCFA to review each patient’s case annually and to report the reasons for not referring patients. Healthcare professionals recognize that the issue of preemptive transplantation raises serious concerns about fairness in access to transplantation. As will be shown in Chapter 10, efforts to increase fairness in transplant access are made through kidney allocation policies.

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<sup>145</sup> When Dr. Julian raised this issue of requiring patients to dialyze prior to transplantation at one selection meeting, Lorna, the head transplant coordinator, plus one social worker appeared to agree with it. Dr. Julian then clarified to the group that he did not agree with the position he raised. Dr. Riley, a transplant surgeon, also acknowledged the benefits of this practice. While most of the team members generally acknowledged the benefits of nonpreemptive transplantation, few believed that it should actually be implemented.



## THE EDUCATIONAL AND REFERRAL PRACTICES BY DIALYSIS STAFF

The first part of this chapter examined nephrologists' decisions about referring patients for transplantation. This section discusses the role of other renal healthcare professionals, e.g., nurses, social workers, technicians, in the educational and referral processes. Very little has been documented about their roles in treatment education and referral. Yet informal interviews and medical chart reviews reveal that these health professionals play an important role in educating patients and deciding whether to refer them to transplant centers. This section does not attempt to provide a complete account of how nurses and social workers interact with patients since that is beyond the scope of this research. However, it is suggested that their educational practices and decisions about referral are important factors influencing access to transplantation to warrant considerable attention.<sup>146</sup> The diversity of educational and referral practices by renal health professionals are presented below to point out ways of improving patients' access to transplantation.

### Pre-Dialysis Classes

Pre-dialysis patients are likely to learn most about their treatment options through attendance at a pre-dialysis class organized by the hospital or dialysis center. At AH, a new policy was established requiring patients to attend the class including even patients who had already begun dialysis. The pre-dialysis class was led by the dialysis social worker and a hemodialysis nurse every first Tuesday of the month, and lasted approximately an hour and a half. The class began by the social worker, Joanne, explaining the purpose of the class:

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<sup>146</sup> There is no single way to represent all nurses' and social workers' educational interactions with patients. Dialysis centers are managed by different companies and may have different training requirements for their health care staff. The dialysis centers I conducted fieldwork in were run by two different companies and the staff employed by the two companies were different in their level of knowledge about transplantation, as evident through informal discussions with them.

"I do this class so that doctors can refer patients to pre-dialysis classes in a relaxing environment, and at a calm pace, and it gives patients a chance to meet someone else, and they don't have to feel like they have to talk at the doctor's level. Patients often have preconceived notions about dialysis which are often incorrect, so I give people a tour, and show the video so you can get an accurate view of dialysis."

This introduction was followed by a brief discussion of HD, PD, and transplantation, a 17 minute video reviewing the advantages and disadvantages of each treatment option, and then further discussion about the options. At that time, the social worker handed out various educational booklets to patients. Next, dialysis patients and transplant recipients who volunteered their time talked about their experiences and answered questions from pre-ESRD patients. The class concluded with a tour around the HD and PD units. Only 28 patients out of approximately 70 new patients per year attended the pre-dialysis classes in 1996. Other hospitals also have pre-ESRD educational programs. Some pre-dialysis education programs in the US are set up to inform patients of their treatment options over the course of two or three visits to "prevent information overload" (Starzomski 1986).

The two presentations observed during fieldwork were without variation and did not seem biased toward one treatment or another by the length of time spent discussing the options. In the video, the options were presented in the order: HD, PD, and transplantation. However, more advantages than disadvantages of each option were discussed. The video only interviewed people who appeared and self-proclaimed to be adapting positively to each modality thereby limiting the viewer's awareness of each treatment's potential difficulties. Transplantation was presented as just another form of treatment. The social worker explained that "Some patients feel that the natural progression of things once they are on dialysis, is that they are expected to go for a transplant, but it depends on the individual patient."

Three male patients in the study, however, had at one time picked up the idea that transplantation was a "cure-all," and for one, Richard, this view remained despite their

educational meetings with renal clinicians. According to a transplant coordinator, Nancy, and a dialysis social worker, Joanne, many patients, especially younger ones, believe that transplantation is a cure-all for their physical and psychosocial ailments. The transplant coordinator proposed that patients get this idea from the media and from hearing people talk about getting a transplant as a lifesaving kind of a procedure.

### **Education Practices of Dialysis Staff**

Facilities differ with regard to whether nurses or social workers play a larger role in educating patients about treatment options. When there are new patients, nurses talk to them within 1-2 months of starting dialysis for their mental state to become clear to learn of their treatment preferences. A different social worker, Debbie, waits to discuss treatment options with new patients after their sixth week on dialysis because otherwise there is little that patients can absorb beforehand since they are trying to get used to dialysis.

One case illustrates this process: I had asked Joanne, a dialysis social worker, why Dr. Olson had not told Luke about transplantation yet and she speculated that the patient was not stable enough for the nephrologist to consider discussing transplantation with the patient. Luke expressed frustration to me and Joanne that no clinician would explain how he could get a transplant. Joanne said that Luke had not originally “seemed motivated.”<sup>147</sup> She perceived his lack of motivation as due to the patient’s depression, but he seemed more motivated now. Joanne refers patients to the transplant center if they are young and relatively healthy; for those who she is unsure if they are medically suitable, she tells them to talk to their nephrologist about transplantation.

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<sup>147</sup> This was the same patient described in Chapter 5 who had attempted suicide.

At another facility, the social worker, Theresa, asserted that she encourages patients, *even more than their doctors do*, to go to the transplant center to have their questions answered even if patients are afraid of getting a transplant. At yet another center, the social worker, Brian, said that he always presents transplantation as a treatment option. However, his encouragement for patients to seek one depends on the “patient’s clinical picture and personal organization.” That is, Brian waits to bring up the transplant option if a patient is clinically depressed, has recently transferred to dialysis, and has few family supports. But if a patient expresses interest in seeking a transplant, this social worker tells the patient to have their nephrologist refer them to a transplant center. Yet another social worker, Monica, does not encourage patients to seek transplantation *per se*, but to find a treatment that best fits their lifestyle. She gives patients the transplant center phone number but also tells them to talk to their doctor about getting referred to the transplant center. Clearly, both nurses and social workers educate patients and may refer patients who seem eligible for a transplant, namely those who are young with few medical and psychosocial problems. Nurses and social workers generally will not refer patients who are uncertain about transplantation but will tell them to speak with their nephrologist further.

Besides transplantation, nurses and social workers also educate patients about other forms of doing hemodialysis and peritoneal dialysis. Kanter’s (1985) dissertation on home hemodialysis, entailed a survey of social workers’ perceptions about patients’ decision making for home hemodialysis versus in-center dialysis. He found that social workers believe that dialysis staff’s attitudes about treatment modalities play an important role in how they educate patients about treatment options. Two dialysis nurses (one HD and one PD) interviewed in the present study reported that they were biased towards their respective treatment modalities and

tend to convey the greater advantages of them when educating patients. These findings suggest that dialysis staff's attitudes may inadvertently inform patients' treatment decisions.

### **LTCP/STCP**

As noted in the first part of this chapter, the US government requires dialysis centers to conduct long term care plans annually and short term care plans biannually for each dialysis patient. The purpose of these meetings is to update primary care givers (primary care nurse, social worker, dietitian, technician) of their patient's medical and psychosocial status. The LTCP meeting places greater emphasis on the patient's treatment plans than the STCP while both meetings concentrate on changes in the patient's blood chemistries.

Before LTCP and STCP meetings occur, primary care nurses are required to meet with their group of patients to find out if they are interested in changing their treatment. Only those patients who are medically eligible for a transplant are asked if they are interested in seeking a transplant. Eligibility status is indicated on the patient's previous LTCP or STCP form located in the patient's medical chart. Technically, medical eligibility for transplantation is determined by the patient's primary nephrologist only, and not by the dialysis staff. However, as will be discussed later, observations of the LTCP meeting at AH reveal that dialysis staff may influence nephrologists' determinations of patients' medical eligibility for a transplant. Two nurses have reported that occasionally, they do not have the time to check with patients before the STCP about their treatment decisions. Generally, since nurses see their patients on a daily basis, they are already highly familiar with patients' treatment needs and wishes. According to one nurse, patients who are undecided or refused to seek a transplant generally do not change their mind about it. In these situations, nurses will review the past LTCP and report to the group patients' wishes as stated on that form.

That nurses only consult with new patients or those who are medically eligible for a transplant about the prospect of getting a kidney transplant presents a problem. Those who are technically medically eligible for a transplant but who are determined by their nephrologist to be “ineligible due to noncompliance,” as discussed earlier in the chapter, might not be informed of their treatment options for many years. In other words, labeling a patient as ineligible for noncompliance reasons may perpetuate a system whereby some patients are rarely and poorly educated about their treatment options and not referred to a transplant center on a timely basis.

There is considerable variation in how nurses in this study respond to patients after learning about their interest in a transplant. At all dialysis centers affiliated with AH, nurses who are highly informed about transplantation directly refer patients to the transplant center by providing the telephone number and contact person for patients to call. It is up to patients to make the phone call. At another center, nurses are not well informed about transplantation; notably, they are unaware of how patients get onto the transplant waiting list. At that center, nurses refer patients who are interested in a transplant to a patient educator who is employed at the facility to further educate patients about their treatment options.

There is also some variation in nurses’ actual referral practices regarding patients’ noncompliance behavior. On the one hand, two nurses said they refer all medically eligible patients regardless of noncompliance behavior because, as one nurse said, patients should be given the chance “to turn over a new leaf.” One nurse reported that she will tell noncompliant patients who are interested in a transplant to speak to their nephrologist about transplantation instead of referring the patient directly because of uncertainty about such patients’ medical eligibility. On the other hand, there were two dialysis nurses who related that they do not refer patients for transplantation if they have been noncompliant. Most nurses expressed concern

about referring noncompliant patients to the transplant center because of the understanding that they will not comply with their medications following transplantation. It is unknown whether nurses who do not refer noncompliant patients base their decision solely on their knowledge of the patient's compliance history or on the patient's past LTCP that specifies "medically ineligible: due to noncompliance." A study of nurses' evaluations of dialysis patients' compliance found that nurses' personal knowledge of patients' lifestyle and behavior, together with data from the medical record, informed their evaluations of patients who were noncompliant (Edelman, et al., 1996). This suggests that personal judgments may slip into the evaluation and referral process.

One problem with the relationship between patient referral and noncompliance is that there is talk among dialysis staff that the patients who engage in the most noncompliant behavior are inner city patients who are predominantly of minority or lower socioeconomic status backgrounds. Nephrologists, social workers, and nurses have made reference to differences in compliance behavior between the dialysis centers in the inner city and those in the suburbs; the former centers treating more noncompliant patients than the latter. If minority groups are less compliant, they are less likely to be referred for transplantation.

The role of dialysis staff in evaluating patients' LTCPs and STCPs during those meetings is important for understanding more about the referral process. Those (ideally) present at the interdisciplinary meetings, held in a conference room, included the medical director (nephrologist), primary care nurse, technician, dietitian, and social worker. LTCP meetings involved reviewing each patient's dialysis regimen, updating medication and dietary prescriptions based on recent changes in blood chemistry values, and determining whether transplantation has been offered as an option. It is during these meetings that nurses report their

patients' treatment preferences to the rest of the staff. While the function of the meetings was similar at both facilities, the sites differed in the manner and tone in which this work was carried out. The issues that arose at the meetings tend to make their way back to the primary nephrologist. Dr. Julian mentioned that based on the notes he receives, social issues preoccupy the meetings, or that the content of the meetings is directed more toward social issues.

It became apparent through observations of LTCP meetings that evaluations of patients' medical status for transplantation were made through a negotiated social process. It was negotiated in that there were propositions and counter-propositions and then resolutions about patients' transplant eligibility. It should be noted that this was done not within the mind of a single clinician *per se*, but among a group of dialysis professionals who interact with patients on a daily basis. Non-physician or non-nurse staff members made conclusions about patients' eligibility for a transplant. This practice was unexpected since it is the policy for nephrologists to make this determination according to a patient's medical condition. It is likely that the basis for staff's involvement in decision making was their familiarity with patients.<sup>148</sup>

The following three dialogues between the nephrologist (MD), social worker (SW), and technician (tech) illustrate the social nature of determinations of transplant status:

#### Dialogue 1

SW: Would she ever be a transplant candidate?  
MD: I don't know her very well.  
Tech: I'm sure she can, she's only 49.

#### Dialogue 2

MD: Is she a transplant candidate?  
SW: I can't think of... we don't know if she was ever referred or evaluated. I don't think so. I don't think she's interested, but I'm not sure.  
MD: I need a new LTCP form, the old one was lost (from 3 months ago).  
SW: You don't think she's a candidate?

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<sup>148</sup> Similarly to how health care providers can assess some aspects of patients' typical patterns of clinical responses to treatment by observing and knowing the patient as a person over time (Tanner et al. 1993), it makes sense that dialysis nurses can assess patients' eligibility status for transplantation.



MD: Well, she's got type 2 diabetes [lists other medical problems]...

### Dialogue 3

MD: How old is this guy?

SW: 70 at least.

MD: So he's not transplant material?

SW: No, dementia.

As these dialogues show, the social worker or the technician may make the assessment that a given patient is suitable for a transplant based on the patient's age or mental status, rather than on purely medical comorbidities.

### **Anomalies in LTCP and STCP Forms and Their Implications for Patient Referral**

The assessments of patients' eligibility for a transplant as stated on their LTCP forms were occasionally different from patients' stated treatment preferences, thus revealing inconsistent evaluations. In this study, patients' treatment status has been categorized in terms of their decision or frame of mind regarding their treatment of choice, given medical eligibility for transplantation.

In contrast, the LTCP categorized patients' treatment status based on actions patients have taken toward obtaining a given treatment. For instance, two patients were noted as medically eligible in their LTCP, but when approached for the interview, their nephrologist had told them that they were too old to get a transplant. One of these patients said that she even wanted a transplant but her chart said she did not. Four patients were originally listed in their LTCP form as "undecided" or "refused to seek a transplant," but were actually in favor of seeking a transplant. Virginia had been marked as "in the process of seeking a transplant" when in fact she was against it. Two patients approached for this study were marked as "in the process of seeking a transplant" but were not eligible, and another patient approached for this study had no status demarcated on his record. That patients' transplant candidacy status is classified as

unknown by dialysis centers has been shown to occur elsewhere, notably among 1,333 of 8,315 patients (16%) (Soucie, et al., 1992).

These discrepancies between patients' LTCPs and their actual treatment statuses may be explained by several practices. First, mistakes on LTCPs could have been made by human error when entering the patient data into the medical record. Second, the physician and/or dialysis staff involved in updating LTCPs could have correctly assessed the patients' treatment status but patients may have changed their mind, meaning that LTCPs quickly became outdated. Third, the physician and/or dialysis staff involved in updating LTCPs could have made an incorrect assessment of the patient's treatment status, perhaps based on LTCPs from prior years. The second practice seems highly likely given the high rate of changes in treatment decisions patients made during the six month period of time they participated in this study, and even prior to that time (see Chapter 8).<sup>149</sup>

Occasionally patients who wish not to seek a transplant inform their physician to not broach the topic of transplantation with them again during clinic visits. Conversely, patients who wish to seek a transplant often stop having discussions about transplantation with their physician because they are already on the waiting list. In the interim, however, patients may change their mind without their physician knowing for at most a year (given that physicians review each patient's LTCP annually). Since patients may change their mind even several times within a period of a year, LTCPs may quickly become outdated. The implications of erroneous LTCPs are simple yet serious: patients may be referred later than sooner to a transplant center for evaluation. This possible outcome contradicts the very purpose for which LTCPs were designed

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<sup>149</sup> Since this study examined patients' and health care professionals' decisions for treatment of ESRD rather than medical records *per se*, it was not feasible to conduct a full investigation of discrepancies in medical records with physicians' and patients' decisions. Further study would be useful in explaining why these discrepancies exist and whether they contribute to problems in referral and ultimately in access to transplantation.

-- to ensure efficient referral of patients to transplantation. The solution may be to increase the frequency with which LTCPs are reviewed and updated to better account for changes in treatment decisions. Doing this would facilitate referral to transplantation should patients decide to seek a transplant.

### **Summary**

In this chapter we have covered a second key way in which nephrologists may influence patients' access to transplantation: by (not) referring patients to transplantation centers. Like Chapter 6, this chapter has presented some subtle evidence suggesting that nephrologists engage in the role of gatekeeper to kidney transplantation. While nephrologists report that they always refer patients to transplantation, there is some evidence to the contrary. Among nephrologists and dialysis clinicians, nonmedical patient factors, particularly noncompliance, effect their decisions about how they refer patients to transplant centers, namely, by making note of it in the medical record. These decisions, it is argued, are likely to effect the treatment patients ultimately receive and transplant professionals' decisions about placing candidates on the national transplant waiting list. The next chapter examines many factors that influence transplant professionals' treatment decisions.

## **CHAPTER 10: TRANSPLANT PROFESSIONALS' EVALUATIONS OF MARGINAL PATIENTS FOR TRANSPLANTATION**

In the last chapter we learned that nephrologists reportedly refer most of their ESRD patients who desire a transplant, even marginally suitable ones, to the transplant center. Since not everyone is eligible for a transplant, it is up to the transplant team to determine who is the most “appropriate” candidate. The purpose of this chapter is to examine how transplant professionals make decisions about wait-listing marginal patients for kidney and kidney-pancreas transplants. This examination focuses more on the psychosocial rather than the medical criteria used to evaluate patients. The process of selecting patients for transplantation constitutes one step in the allocation of scarce resources.

Throughout this chapter, transplant professionals’ decision-making process is shown to be guided by a utilitarian theory of justice, as defined in Chapter 4. In other words, the team does not discuss cases using bioethical constructs, but their decisions can be characterized as utilitarian. The transplant team seeks to maximize the greatest good for the greatest number of people by minimizing harm, e.g., minimizing waste. They do this by *forestalling* (not necessarily preventing) patients with certain contraindications to transplantation (e.g., a history of noncompliance, ambivalence) from getting wait-listed to reduce the chances of “kidney waste.” In effect, the team believes it increases the chances that transplanted kidney grafts will last longer by wait-listing those patients who are healthiest and most desirous of a kidney transplant.

There are several important themes which appear throughout this chapter. These themes pertain to the measures the team relies on to make deliberations about the contraindications presented by marginal patients. As noted in Chapter 4, allocation decisions are based on material or microallocation principles (e.g., social, sociomedical, medical, personal, and impersonal

criteria) established by tradition, moral or legal principle, or by policy. As will be shown below, the transplant team relies on, to different degrees, the transplant center tradition, moral codes, and *de facto* and *de jure* policies to make decisions about wait listing patients. Certain contraindications to transplantation are evaluated by *de facto* policies while others are evaluated by *de jure* policies. A key issue is that while the *de jure* policies are more likely to be based on “objective,” scientific data to support the importance of some contraindications, the *de facto* policies tend to be based on vague, ambiguous, and subjective considerations in support of other contraindications.

In the case of the *de facto* policies, cultural values especially play a significant role in the team’s deliberations. The propensity for cultural values to permeate the evaluation process is driven by the fact that there are no standardized methods for transplant professionals to medically and psychosocially evaluate whether to place patients on the waiting list; rather there are only proposed guidelines (Kasiske, et al., 1995; Flechner 1994). In a study of renal transplant programs (n=154) only 7% indicated that they have formal criteria for candidate selection (Levenson and Olbrisch 1993). Most programs use informal psychosocial criteria for selection (Levenson and Olbrisch 1993). In fact, transplant centers have been shown to place different amounts of weight on various contraindications (Ramos, et al., 1994).

Specifically, this chapter contends that cultural values of ‘conservation of scarce resources’ and ‘personal responsibility for health care’ compose the utilitarian discourse in evaluating patients. Deconstructing these and other cultural values is important to do because they may inadvertently act as barriers to patients’ access to the waiting list. What follows is a brief description of the patient work-up to get onto the transplant waiting list, and of how transplant selection meetings work. The next section presents an examination of how transplant

professionals decide whether to place marginally suitable patients on the transplant waiting list. Actual cases covered during these meetings are presented to illustrate specific points about the transplant professionals' values and the decision-making process. The chapter concludes by setting forth five key points about the implications of the transplant team's decision-making process.

### TRANSPLANT SELECTION MEETINGS

The majority of kidney patients who have been worked-up and evaluated for a transplant are placed on the transplant waiting list without requiring discussion at the transplant selection meetings. The transplant center evaluates approximately 125 new patients a year and 100 of these are placed onto the list. Only the cases of kidney patients who are considered marginally suitable for transplantation and all kidney-pancreas (KP) patients are reviewed during transplant selection meetings to determine whether or not they should be placed on the waiting list. Marginal patients are those who are older, or who have significant underlying medical problems such as heart disease, vascular disease, liver disease, diabetes or obesity. According to Dr. Riley, a transplant surgeon, marginal "doesn't mean we'd say no [to wait-listing them], it just means they're at a higher risk to have a problem."<sup>150</sup>

Transplant selection meetings take place once a month in a conference room in the transplant department. They usually last an hour to an hour and a half in the afternoon, depending on the caseload. The meeting was canceled several times because Dr. Benton, the director of the transplant department and the head surgeon, was out of town on business, on vacation, or busy performing an operation.

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<sup>150</sup> This surgeon noted that other transplant centers do not necessarily transplant marginal patients.

The transplant selection meetings were virtually always attended by Dr. Benton. He sat at the head of the table. To his right sat the medical secretary, Rose, and the head nurse manager for transplantation (a transplant coordinator), Lorna, sat to his left. All other participants including, another transplant coordinator, one of the social workers, one or both of the transplant nephrologists, and occasionally, another transplant surgeon, Dr. Riley, sat randomly around the table.

Dr. Benton ran the meeting, but in a coordinated fashion elicited and incorporated the team's input. The transplant professionals thought of themselves as a team. Dr. Benton was obviously the one in charge: when he arrived, the meeting began. He began each case by saying the patient's name. To invite the team's comments on a patient, he asked the following types of questions: "Jones, any issues with him?" or "I bring her up because I just saw her. She's massively obese at this point. She needs to lose weight before a transplant. Anyone have any strong anti-opinion?" Dr. Benton was also the one to have the last word: e.g., "list her" or "put him on hold." Medical literature on healthcare teams reveals that physicians' control in medical practice includes the "power to define what medical services will be legitimated as necessary" (Aries and Kennedy 1986:205).

The transplant professionals had different degrees of involvement in the selection meetings. The team members who had the most clout and thus participated the most in discussion included the transplant nephrologists and the head transplant coordinator. Lorna voiced the most concern about conserving the transplant department's financial resources and was often quick to point out when a patient's condition could lead to the waste of transplanted kidneys. The team members who seemed to hold the least authority in decision making were the other transplant coordinators, social workers, and medical secretary. Yet Dr. Benton often called

upon the social worker for input on a patient's psychosocial and financial background. The medical secretary, Rose, often chimed in to provide background information on patients and to clarify issues about transplant-related policies. The other transplant coordinators provided the least verbal input to discussion.

The transplant team spent variable amounts of time discussing patients. For some, they deliberated over several minutes,<sup>151</sup> others were debated in seconds, and a few patients were even brought up only to point out what medical exam needs to be done for the patient, case closed. Lorna stated that the team rarely disagreed about who will get on the waiting list except those who in the past have been chemically dependent or noncompliant. In between, or even during discussions of the cases, the team members interjected witty remarks, enjoying a moment of comic relief in the face of ethical dilemmas, failing patients, and a pile of charts stacked a few feet high. Although Dr. Benton tolerated, and even contributed to the light banter, when he was out of the room, conversation became more informal.

Overall, the team members interacted relatively informally with each other. They addressed each other by their first names. As an outsider to the transplant department, the investigator was permitted to address those team members who were not physicians by their first name.<sup>152</sup> The use of first names with these transplant professionals (three female transplant coordinators, two male social workers) reflects a status, and possibly a gender, hierarchy within the department. This hierarchy corresponds with the status system within medicine in general, which accords greatest status to those who have undergone the longest periods of training (e.g.,

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<sup>151</sup> Deliberations of several minutes over one patient is considered a long time in this context.

<sup>152</sup> Interestingly, despite the use of the title "Doctor," I developed better rapport with more physicians than with non-physician transplant professionals. While I met with each team member several times, this greater familiarity with physicians may be due to the fact that I shadowed them in patient clinics.



physicians) and those who practice the most invasive technological interventions with patients (e.g., surgeons) (Stein 1990). The latter quality is accorded high status because it approximates the American biomedical value of activity and mastery over the body and illness (Stein 1990). In addition, “the ‘higher’ the technology, the more elevated the status” (Stein 1990:83). Given this status schema, the descending order in which team members can be ranked is: surgeons, nephrologists, nurses, and social workers.

Prior to the selection meetings, the surgeons review the medical records of all kidney or KP patients who have completed their evaluations to determine whether any patient issues require review by the team. The reasons for bringing a patient to the committee include problems regarding a patient’s medical status, age, obesity, drug use, finances, and less often, noncompliance, motivation, and status as a foreign national. Many, if not most, of the marginal patients reviewed are ultimately wait-listed. Some, however, were put on “hold.” Those who were placed on hold generally had to either go through additional medical examinations like cardiac catheterizations, or lose weight, or prove that they were drug free or compliant enough for a set period of time. Other patients on hold included those on the transplant list who developed a medical problem that temporarily precluded transplantation and whose status was expected to change within a year.

For example, someone who has had a myocardial infarction would be placed on hold for six months until they are stable enough to be officially reactivated on the waiting list for a transplant. Patients on hold do not lose any of their accrued waiting time. In addition, patients can remain on hold for an indefinite amount of time. Dr. Benton explained the logistical practicalities of putting someone on hold: “So rather than getting calls every other night from the organ bank, we put them on hold. That way they don’t have to get up every night excited.”

Some patient cases are “tabled” or require further evaluation before the team makes a final decision about wait-listing them. Patients who are tabled require, for instance, additional cardiovascular laboratory exams or consults with transplant professionals. Patients who are considered eligible for a transplant are notified of their status after they have been placed on the waiting list. Unsuitable patients are notified of their status by a letter from the transplant surgeon or informed in a meeting with the surgeon after the committee meeting.

### TRANSPLANT PROFESSIONALS’ DECISION MAKING ABOUT MARGINAL PATIENTS

This section delineates each type of contraindication to kidney transplantation that requires transplant committee review. These contraindications include problems with medical status, age, physical size, drug use, psychosocial stability, noncompliance, ambivalence, financial stability, and foreign nationals. Using actual case examples will reveal the ethical dilemmas and cultural meanings they represented, and how the team resolved the issues. Many of these contraindications raise at least one important issue and present a problem regarding difficulties in access to the waiting list. As will become apparent, there is an overarching concern that transplanting marginally suitable patients will lead to the “waste” of a kidney. Many of the issues each case raises are interrelated, particularly those that pertain to psychosocial issues.

#### Medical Contraindications to Transplantation

The most important medical contraindications to kidney transplantation are cardiovascular and peripheral-vascular problems. People must have good cardiac function to be able to withstand the stress of surgery and fluid shifts.<sup>153</sup> The team relies on cardiologists to inform them of the odds of certain patients having a ‘life-threatening cardiovascular event’

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<sup>153</sup> A fluid shift occurs when fluids shift position within the body. A drastic increase or reduction in fluids can adversely affect cardiac function.

within 6 months or 1 year of transplantation. If the odds are high (e.g., 10%-15%), then the transplant team will not transplant patients because it would be considered a “waste” of a kidney should the patient die, as Dr. Benton noted.

In addition, patients are not eligible if they have had a recent malignancy. There are different policies depending on the type of cancer; for some tumors, patients are required to wait two to five years before becoming eligible for a transplant. Further, comorbidities, e.g., diabetes, may preclude patients from being transplant candidates. Dr. Benton explained the process of evaluating patients from a medical perspective, indicating how the process has changed over time:

“Well there are several things we look for. First and foremost, is there a medical condition. Do they a) need the transplant. In other words, are they an appropriate candidate from a medical point of view. And then b) are they healthy enough to undergo the transplant. The first is very easy to determine. The second is subtle. And the reason it is subtle is because over the years we’ve become more aggressive in transplanting more and more people with diseases of other organs. For example, we’ll transplant people with coronary artery disease, previous myocardial infarctions, we’ll transplant people with a history of cancer as long as it appears to be cured, quiescent, whereas 10 years ago, we might not have done that. We’ll do that now.”

The basis for ensuring that patients have no medical contraindications to transplantation is to increase the chances of patients having a successful transplant, which means greater than one year graft survival.

A major finding of this research is that transplant professionals are concerned about issues other than or contingent upon patients’ well-being post-transplant in their assessments of patients’ suitability for transplantation. This point pervades many of the discussions about all types of contraindications to kidney transplantation. Specifically, the team is concerned about the transplant center’s statistics, accreditation, and insurance coverage. These factors can be jeopardized by transplanting patients who are deemed too marginal and thus unlikely to survive

past a given critical point, which in turn gives the center a low survival rate. Consider the following case:

- Dr. Benton: I told a 43 year old diabetic male with MI and bypass [not to get a transplant]. I didn't think he was going to be a transplant candidate based on this [medical history]. He was irate because [the cardiologist] said he was OK. I told him he's at risk to die in the next year. CMC had already turned him down. This guy's wife now wants to give him a kidney. [He referred to a similar case:] CR, we did this last year. Six months later the patient died. The wife said isn't that our risk to take?
- Dr. Julian: [We should] stick with our guns. We're getting burned with deaths.
- Dr. Benton: We ruled out KP on marginal hearts because of post-op not interoperative problems. Do any of you guys think you should see him? The wife is very sophisticated medically. The bottom line is I think we could do it-- but [there's a question of how he'll do after the operation. If he died right away it would affect the living-donor statistics making them comparable to cadaver-donor statistics, 'UNOS would ding us.']. The stats have to be pristine or else we don't get paid and approved. I'll tell [the nephrologist] to stick to his guns.

This case shows how the transplant team is weighing the transplant center's interests and the patient's best medical interests from the physician's point of view against the patient's treatment preferences. Transplanting this patient poses a risk to the patient and consequently a risk to the transplant center in that early post-transplant death lowers transplant center survival statistics and thus transplant center financial stability. While the transplant team would like to give a transplant to this patient, they decide to err on the side of being conservative. They raised the point about the patients' wife being "sophisticated medically" because such patients can partially persuade team members to carry out their wishes. And in this case, the team was leery of being persuaded to follow a course of action that could ultimately harm the patient. This case also represents the implementation of a *de facto* policy of being cautious in light of high risk patients. That the team even considered the possibility of transplanting the patient underlines the fact that there is no steadfast written rule against transplanting high risk patients, but that the team ultimately "sticks to its guns" about protecting the patient from premature death as well as the transplant center's statistics.

One year and preferably two years is the standardized acceptable time for kidney graft survival. But when transplant professionals talk about a six month graft survival, it is not literally considered an unacceptable time cutoff. Rather, transplant professionals rhetorically speak of a six month graft survival to convey the idea that such a limited time of graft survival is a “waste” of a kidney. This perspective was apparent in the case above, as presented by the surgeon’s comments.

Patients and transplant professionals may differ in their interpretations of a six month graft survival. Transplant professionals may see this situation as a waste of not only the kidney that could have survived longer in a healthier patient, but also of transplant center, local OPO, governmental, and UNOS resources. It is questionable whether patients would agree. The wife in the case above argued that she and her husband should be allowed to make a decision about taking such a risk.

As noted in Chapter 7, many patients reported being willing to undergo a transplant knowing that it would last less than a year because they were desperate for a reprieve from dialysis and its concomitant lifestyle habits. This difference represents a potential conflict of values of transplantation: whereas the primary concern for transplant professionals is longevity, many patients primarily value quality of life.

### Age

The patient’s age is another medical contraindication to kidney transplantation.<sup>154</sup> There is no age limit *per se*, but the early 70s tend to be the cutoff.<sup>155</sup> AH takes each case individually.

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<sup>154</sup> Turning from wait-listing to allocation practices, transplant professionals also make an effort to increase the efficiency of transplanted organs and avoid waste. Specifically, the transplant center tends to give older cadaver donated kidneys to older transplant recipients, and younger cadaver donated kidneys to younger transplant recipients. The reason for doing this is because kidneys age. Giving an older kidney to a younger patient increases the chance of graft failure soon after the transplant. Conversely, giving a younger kidney to an older person may “waste” the extra years of graft survival in a patient who is likely to die from old age.

The age limit for patients awaiting a cadaver donor is lower than for those awaiting a living (related) donor because there is a greater likelihood of success with living donors for older patients. In addition, transplant professionals take into consideration that older patients awaiting a cadaver donor are less likely to be medically suitable for a transplant by the time a cadaver kidney becomes available, several years later since the likelihood of success diminishes as patients age. Thus, they are reluctant to wait-list patients older than 70 because by the time they receive a cadaver donor kidney at age 73 to 75, they will be too old to undergo the surgery. Furthermore, older patients run the risk of having more infections and thus rejecting their kidney.

Dr. Benton gave a detailed synopsis of how he assesses age and the medical considerations:

"We look at age to some extent in that we know full well that the older patient presents us with a double-edged sword. On the one hand, because they're older, they're less likely to be able to tolerate complications, whether they are surgical or medical. On the other hand, they're not going to reject their organs. So it's an attractive situation because we know that rejection is very unlikely. As the body gets older, the immune system ages just like everything else, and as the immune system gets older, it's less likely to be able to mount a successful rejection reaction. This is very well evidenced by the fact that people in their 6th and 7th decade have an incidence of rejection after transplant of less than 10%. So rejection is very unlikely in older patients but they also are more likely to have other complications. So from a risk point of view, from a pure biology of transplant rejection, they are a very good risk group. But we have to look very carefully, is this a patient who is going to have a myocardial infarction *6 months after the transplant and waste an organ*. So we look very carefully in the older group for any signs of a bad heart or bad lungs or any previous cancer. We don't have an absolute age cutoff in our program, I'm sure some do. But we really try to discourage referrals of people over the age 70 unless the nephrologist believes they're in really an excellent condition. And the main reason for that is that in [this part of the state], waiting time is 3-5 years for a cadaver kidney. So if you get somebody referred at the age of 72 or 73 and they're marginal, then the odds are very strong that 3-4 years later, when they finally get matched, they're going to come in and really be in bad shape. ... So we know that there is definitely an age, after 60 somewhere where you shouldn't transplant people, but it's just hard to know exactly what it is, so in our center we don't have a hard and fast age rule, we just individualize" (emphasis added).

The following case illustrates the concerns about patient safety and waste of kidneys for elderly patients:

Dr. Benton:	JC. Marginal patient.
Dr. Ingel:	71 year old male lawyer.
[Someone]:	[He's] not on the list.
Dr. Benton:	The issues are age, functional status is poor, chair bound, neuropathy, and noncompliance.
Lorna:	What's his blood type? If he's type O, he's not going to get one!

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<sup>155</sup> The age cutoff in Western Europe is much lower; there is reluctance to transplant patients older than 50 or 55 years of age (Dennis 1995:140).

- Dr. Benton: His other doctor waited until getting a cardiac catheterization. Here's again the dilemma- We know in our hearts we shouldn't list him but there are no hard rules/reasons to say why. He will only get cathed until after he's on dialysis.
- Dr. Julian: Are you sure you don't want to have a policy: over 70 and don't do a transplant?
- Dr. Benton: I still think we need to individualize.

In this case the transplant team takes into consideration the patient's blood type when deciding whether it would be worthwhile to put him on the waiting list. The team is presented with a dilemma of not having sufficient knowledge about the patient's cardiac status because a certain test can only be conducted safely after a patient begins dialysis. To deal with this uncertainty, the transplant nephrologist suggests establishing an objective criterion of an age cutoff at which to deny patients a transplant. But the transplant surgeon persists in evaluating patients on a case by case basis. This is a clear example of a *de facto* policy of individualizing each case evaluation. This comment represents the concern mentioned earlier about wasting kidneys as a problem in its own right and in relation to transplant center statistics. In a similar case about a 72 year old man, Dr. Benton noted, "I'm not worrying about the transplant but him dying six months later and wasting a kidney."

### Obesity

Obese patients are high risk transplant candidates. Obese kidney recipients have higher rates of surgical and infectious complications because they run the risk of having their wounds dehiss (separate post-transplant). Dr. Benton further explained the problems of obesity in terms of the medical contraindications and technical difficulties in carrying out the transplant itself:

"Yes, people who are obese clearly have a poorer track record. The data are very clear about that. I just reviewed them last week. The people who are more than twice their ideal body size have a significantly poorer outcome with any kind of transplant. The reason is probably several fold, but most importantly is technical. The surgeon has a very difficult operation to perform, and therefore has a much higher rate of technical failure, so that the loss rate is early on, but it's real. There are practical issues too. In order to do a kidney transplant for example, a patient needs to be biopsied from time to time that rejection is an issue. When the patient is obese, we can't biopsy them easily without radiographic guidance. The CT machines have a 300 lb. limit on them. So we have pretty much in our program a 300 lb. absolute cutoff. And, more than that for smaller people. We have refused transplantation to some people, primarily women, who are in the 5' to 5'5" range if they are over 250 to 275 lbs. because in essence they're posing the same problem. We have been very aggressive in our center about transplanting large people. In fact we

have taken referrals from other local transplant centers where patients have been refused a transplant because of obesity and we've done them. So we will stretch our limits, but we do know that it's a definite risk factor and we do have a cutoff of absolutely 300 lbs. And we tell people we will not put them on the list until they're below that. At many centers their limit is much lower than that."

Those who are obese are required to make a behavioral modification before they can be listed for a transplant. The transplant team gives obese patients a target weight they must reach before being officially wait-listed. The target weight varies among patients. When patients lose enough weight, they are required to contact the transplant center to get reevaluated and have their names activated on the waiting list. Otherwise, if patients have not contacted the center, Dr. Benton explained, "We from time to time go through our charts and we see that we have these people who have completed their work-up and are not on the list, we'll ask them every six months to come in and get weighed and so forth." Unfortunately, one transplant nephrologist, Dr. Alland, recounted that he has a low success rate in getting patients to lose weight, and Dr. Benton noted that obese patients usually become bigger rather than smaller over time. The following case illustrates how the transplant team addresses the issue of obesity in selection meetings:

Dr. Benton: BW, woman, 5'2" and 250 lbs, has coronary artery disease. I'm not sure if she should be listed. Age 61.

[Discussion of BMI- body mass index.]

Dr. Benton: [Told Rose to get a BMI chart.] There is a poor survival above '35' BMI for transplantation. Over 35 BMI is a 50% rejection/acceptance rate. A 50%-60% graft survival -- that's a waste of kidneys.

In this case we see that the team assesses whether to list an obese patient based on a putatively objective measure -- the BMI chart -- while also relying on statistical analyses of survival outcomes. Other transplant centers have defined obesity as a BMI greater than 30 and morbid obesity as a BMI of 35 and over (Holley, et al., 1998). The determination that a 50% survival (or rejection) rate is a "waste" of kidneys is significant because some patients may find it a worthwhile chance to take.



The contraindications to kidney transplantation discussed above are more objective or cut and dried than the contraindications presented below. The transplant team engages in greater moral deliberation particularly with cases of drug use, psychiatric problems, and noncompliance.

### **Drug Use**

Patients' past and current use of drugs and alcohol is an important factor taken into consideration when evaluating whether to wait-list patients. Those who are actively using drugs or alcohol are not given transplants. They are put on "hold status" rather than on the active transplant waiting list until they have shown that they are drug free. Since drug and alcohol use is seen as a "chemical dependency" problem, the transplant team requires patients to provide evidence that they have stopped drinking or using drugs.<sup>156</sup>

The reason for not transplanting drug users is not because the drugs or alcohol harm the transplanted kidney *per se*. Rather, the policy is in place because alcohol and drug users are seen as highly likely to not comply with their medicine regimen post-transplantation. According to David, a transplant social worker, transplant professionals are wary of drug users, even if they have gone through rehabilitation because they tend to start using drugs again which leads to noncompliance and kidney rejection:

"If they're just out there wantonly getting high and not conforming to our expectations and requirements, it's conventional wisdom that someone who is doing that does not have a good potential for doing a successful recovery. I guess you could clean up someone who does a lot of drugs, you could de-tox them for a few days, give them a transplant, send them home, but that person could be using again and having complications and not taking his medicine, and rejects the organ, so you've wasted that organ."

Alcoholics pose a more difficult problem for evaluation by transplant professionals than do drug users. Dr. Benton noted why:

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<sup>156</sup> In contrast, liver transplant patients are required to sign a contract that stipulates that they be enrolled in an alcohol or drug rehabilitation program, and be drug-free for at least six months.

"Alcohol is hard because it is a legal substance, and I think that's where it becomes difficult. If we believe somebody is an alcoholic, we will send them to an alcoholic specialist and get an opinion. If the opinion is this person is very likely to noncomply, very likely to continue being an alcoholic, we won't transplant them."

According to David, the fact that a person drinks alcohol does not preclude the possibility of getting a transplant. Rather, the issue is

"A matter of how much, what else is there besides drinking. So if someone is smoking a lot and drinking a lot and running out to the race track every other day, I mean, that kind of person is not going to be a great transplant candidate. Because the job in someone who receives a transplanted organ, their job for at least the first month and usually longer, is to work their recovery. That's their job. They're not working, right? And they should, their job is to follow the regimen so that the transplant is successful and that side-effects or complications are identified quickly and dealt with quickly."

These comments reveal a moral concern commonly raised by transplant professionals, namely, the importance of taking personal responsibility for one's own health. Some bioethicists and health professionals contend that patients who have been responsible with their health should have priority in receiving scarce health care resources (e.g., liver transplants) over those who have been irresponsible because the latter caused their medical problem and thus contributed to the growing demand for scarce resources (Smart 1994; Kluge 1994; Ubel, et al., 1993).<sup>157</sup>

The issue of personal responsibility is less directly applicable in the case of kidneys since patients' behavior (e.g., drug use) does not cause kidney failure, unlike liver disease.<sup>158</sup> However, there are subtle ways in which the value of personal responsibility is woven into the transplant team's evaluation process. In the case of drug users seeking kidney transplants, the team requires that they learn to take personal responsibility for health, by becoming clean and sober, before being wait listed. If patients cannot get through the required drug program, the team will not wait-list them.

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<sup>157</sup> See Atterbury (1996) for criticism of using personal responsibility as a criterion for allocating scarce health care resources.

<sup>158</sup> In this study, some dialysis nurses expressed the view that dialysis patients are responsible for causing their kidney disease since ultimately they were noncompliant with their medication or dietary regimens allowing their high blood pressure or diabetes to result in kidney failure.

We can problematize the notion of personal responsibility further by considering other cultural threads about taking responsibility for health woven in the transplant team's comments above. First, it is plausible that the team views drug users as irresponsible because they tend not to be productive members of society. The Protestant work ethic is highly valued by some members of US society who adhere to the tradition (Weber 1958; Gaines 1992a). Since transplant recipients can not temporarily work, their new 'job' is to 'produce' their recovery. Yet drug and alcohol users are not good candidates because they irresponsibly fail to meet the demands of holding either type of 'job' because they have alternative priorities. Those who lack the responsibility to take care of themselves are unlikely to routinely take the transplant medicines.

Second, there may be a broader cultural and moral concern among transplant professionals that patients ought to take personal responsibility to care for their transplanted kidneys so that they reduce the extent of organ scarcity. Let us consider now how the team dealt with an actual case of a drug user seeking a transplant.

Dr. Benton: Next patient, GH. I read the note by Dr. B (cardiologist). The patient is on hold for cocaine use.  
 Dr. Julian: Sounds like a drug problem. I think his social situation -- cocaine -- will make him noncompliant. I recommend he be on hold until he's no longer a drug user.  
 Dr. Ingel: He had originally denied using, then had a positive urine screen, but kept denying it. If it's an issue with veracity... If he can make one visit and get a [test done]... If he doesn't do it, [forget it]. If he really wants a kidney, he can jump through that hoop.  
 (All agreed).

This case demonstrates well the interrelationship between drug use, noncompliance, and motivation. The team is willing to give a patient another chance to 'prove himself' by being compliant with an arbitrary requirement (rehabilitation) set forth by the team. The rehabilitation requirement is arbitrary since the length of the abstinence is not based on empirical data; some centers require abstinence for 1 month while others require abstinence for up to 24 months

(Ramos, et al., 1994). In the case above, if the patient fails to accomplish the visit and test because of a lack of motivation to get a kidney, the team will remove him from the list. The assumption here is along the lines of, 'If you're really motivated to get a kidney, you'll be compliant enough to stop using drugs.'<sup>159</sup>

### **Psychiatric Problems**

Patients with a psychiatric history present a concern to the transplant team because of the fear that they will not comply with taking their medications. One transplant coordinator, Kathy, explained why:

"A schizophrenic who hears voices, where the voices say, 'don't take your medicine today' kind of thing... Someone who is manic depressive, may be very manic or so manic that they don't take their medicine, that they are so depressed that they don't take their medicine."

In addition, depression is important to detect before a patient is transplanted because it may hinder people from taking their immunosuppressive medicines or going to their post-transplant appointments. Antidepressant medications can also adversely react to immunosuppressant medications. Patients with bipolar disease are also likely to stop taking their immunosuppressant medicines when they feel better.

The transplant team occasionally encounters patients whose mental faculties or intelligence is questionable. Again, the concern is with compliance with the medical regimen. The following two cases illustrate the diversity of opinions about this issue and how the team suggests ways of resolving it.

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<sup>159</sup> The case and comments made by transplant professionals above indicate that the team maintains assumptions about the "sick role" as outlined by medical sociologist, Talcott Parsons. Specifically, the sick role entails two responsibilities: 1) The sick person must seek and cooperate with resources to eliminate his/her illness; and 2) The sick person must be motivated to abandon his/her illness (Parsons 1958). Patients who do not uphold responsibilities of the sick role have been shown to be treated poorly by medical professionals (Alexander 1982:356). Similarly, drug user patients who do not uphold their responsibilities for getting wait listed are also ultimately denied medical aid.

Dr. Benton: D. Brown, 63 years old.  
 Dr. Julian: This patient has no insight, he assimilates zero, I try to explain the risks and he doesn't get it. It's a question of whether stupidity is a reason [to not list someone].  
 Dr. Benton: But does he have any family?  
 Dr. Julian: I think, let's talk to Kathy and hear if he has family support [to help him out post-transplant].

This is a case in which Dr. Benton did not want to accept an assessment on face value that the patient is psychologically ineligible for a transplant. Instead, he suggested a way to give the patient a chance at getting a transplant by examining other resources in the patient's life, namely, the family. The case is temporarily resolved by having a transplant coordinator investigate whether the patient has sufficient family support to facilitate the patient's compliance with the medical regimen. Consider another case:

Dr. Benton: Lee Fisher, level of understanding.  
 Dr. Julian: [Jokingly says] 'Cause he's a farmer.  
 Dr. Benton: I picked up the vibes the guy doesn't know what he's getting into.  
 Dr. Julian: This is just a matter of him being stupid.  
 Lorna: Some people can follow a schedule.  
 Rose: He lives with his mother. [She recounts how when she called, his mother was verbally abusing him and her on the phone.]  
 Dr. Riley: It's not that clear he understands his medical problems. He doesn't really read.  
 Dr. Benton: Transplant him. The fact that he called you up to apologize doesn't mean he's stupid.

In this case, the team is predominantly leery about the patient's intelligence and understanding of what transplantation involves. The concern is that unintelligent patients will not properly take their immunosuppressive medications and thus cause their kidney to reject.<sup>160</sup> Yet Dr. Benton made the final decision that the patient was intelligent enough, by virtue of his actions, to be wait-listed for a transplant. In both cases the transplant surgeon made decisions that took into consideration the patient's life context. These cases indicate that the potential mis-evaluation of a patient can occur when well-educated healthcare professionals assess the understandings of transplantation in patients with less education (see Lindblad, et al., 1998). In

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<sup>160</sup> Patients with marginal intelligence are a legitimate concern for transplant professionals. Such patients are required to have support systems that are willing to assume the role of responsibility for ensuring that the patients take their immunosuppressant medications, visit the transplant center, etc.

other words, it is as if these patients were being evaluated by the team in terms of how well they approximated the team's understanding of what constitutes intelligent behavior.

### **Social Support**

The social worker assesses the extent of patients' social supports, e.g., family or friends, namely those who patients can rely on for help post-transplant. Social supports are necessary immediately post-transplantation to help recovering patients with a variety of important tasks: transportation between home and the hospital, grocery shopping, running errands, helping the patient walk, emotional support, etc. Transplant professionals believe that social supports also help patients be more compliant in their transplant regimen and medicine taking. The transplant team is not concerned if patients lack support unless they are likely to be noncompliant with the medications. However, social supports are especially important for patients who are dependent on other people, or who may not have a good ability to recall or retain information. According to one social worker, a red flag goes up "If I'm talking to you and somebody else answers the questions" because that other person might not always be available to the patient.

### **Noncompliance**

Noncompliance issues pervaded the transplant meetings. So far we have seen that the team is concerned with transplanting marginal patients for reasons that ultimately have to do with noncompliance and the potential waste of kidneys. Now let us consider noncompliance as a contraindication in itself.

Patients' noncompliance is an important factor in the transplant team's discussions about placing patients on the waiting list. Noncompliance is an important issue in contradictory and cultural regards. First, the team members stated that they would never deny wait-listing patients solely on the basis of noncompliance. Noncompliance compounded other contraindications to

lead the team to refuse or forestall wait-listing patients. The contradictory point is that the team's heavy emphasis in their discussions of noncompliant patients raises doubt that noncompliance plays as small of a role in decisions as the team claims. The discrepancy will be explained at the end of this chapter. The rest of this section explores how noncompliance is important in cultural ways. While the previous chapter deconstructed the moral components of noncompliance, we will now deconstruct some of its underlying cultural assumptions by describing: a) how the transplant team evaluates whether patients are noncompliant, b) the actions they take to encourage compliant behavior post-transplant, c) the team's attitudes about noncompliant patients, and d) the team's decisions about re-transplanting noncompliant patients.

As previously noted in Chapter 9, transplant professionals at AH and other transplant centers maintain the assumption that patients who are routinely or habitually noncompliant on dialysis will be noncompliant with taking their transplant medications, thereby causing kidney rejection. It appears that transplant professionals largely rely on their transplant center's history of experience with noncompliant patients to formulate their opinion on the matter of compliance. Patients who are noncompliant on dialysis raise doubts in the minds of the transplant professionals about "how good of a risk this person is." Since transplant professionals do not want to 'waste' a kidney on patients who they consider 'irresponsible' for not doing dialysis treatments, they have devised certain strategies for maximizing the efficiency of organ allocation from the pre-listing stage. The main issue the team must consider, Jennifer asserted, is, "Is this person going to take their medications after transplant, because that's the number one thing that's going to keep their organs functioning, basically."

The transplant team evaluates noncompliant patients individually depending on the extent of their noncompliance. Those who are blatantly noncompliant are not placed on the waiting list.

Dr. Benton explained that he considers noncompliance last in his decisions about wait-listing patients because it is the most subjective variable due to the difficulty in determining whether someone is actually noncompliant. Nancy, a transplant coordinator, commented how the transplant center is more lenient with patients who have been less noncompliant because of the thinking “you can’t deny a person a transplant because you feel they won’t make it.”

Transplant professionals learn the extent of patients’ past noncompliance with dialysis, diet, and medications by contacting the patient’s nephrologist and dialysis center. Specifically, the team reviews the patient’s medical record and notes from the nephrologist or previous social work evaluations to see if the patient attended dialysis treatments and appointments with doctors, were compliant with the kidney diet, and had family support.<sup>161</sup> The transplant team’s concern with dialysis noncompliance is clear given the ample data, as presented in the previous chapter, showing that patients who are noncompliant with dialysis tend to be noncompliant with their immunosuppressant medications. Sometimes the dialysis center even calls to inform the transplant center of a patient’s noncompliance and says, “oh you shouldn’t do him” meaning, do not transplant this noncompliant patient. Nancy explained how the team has easy access to patients’ records of compliance behavior:

“Well usually, if they’re from this hospital or this dialysis center or sometimes our nephrologists know them from many years of renal disease, they have a history that follows them around. So you kind of go by that. A dialysis center will keep a history of their coming to their visits, or missing visits, things like that. Or, their compliance with diet and fluid restrictions. So you do have a history that follows you around.”

It is evident that patients’ reputations of noncompliant behavior can precede them to the transplant center. Recall the point made in Chapter 5 that a person’s reputation can be seen as a

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<sup>161</sup> It is unknown whether patients are routinely told by dialysis professionals that the transplant center will be notified of patients’ practice of noncompliance. However, patients on the Internet noted that their transplant center informed them that they will consider removing patients from the transplant waiting list if they learn that patients are noncompliant. One patient on the Internet reported that her nephrologist warned her not to engage in dietary noncompliance so as to “build myself up for the transplant.” From the messages on the Dialysis Listserv, it is apparent that at least some patients are aware of the dialysis clinicians’ practice of reporting noncompliant behavior to the transplant center.



source of power. In this context, noncompliant patients appear to have less power than compliant patients to insist on placement on the waiting list because of their tarnished reputation. The “track record” may be particularly troublesome for those who have a recent history of noncompliant behavior.

After learning that a patient has been noncompliant, transplant professionals act as gatekeepers to placement on the waiting list by testing or setting up an informal contract with noncompliant patients. This involves first pointing out to patients their noncompliant behavior, getting them to ‘admit’ to it and to agree to change, and then informing them that they will be tested. This interaction occurs during the educational sessions with the transplant coordinators or physicians. This discussion arises when, for instance, transplant coordinators emphasize the importance of being compliant to patients who have been noncompliant on dialysis. As Nancy pointed out:

“...You kind of allude to the fact that the history that has followed them around hasn’t been the greatest. And you would fill them in on all of the things that they would have to do after this transplant to keep this transplant going. And you ask them if they’re in agreement, really, and if they think they can do that well.”

The test involves seeing if patients can become more compliant with their dialysis treatments or physician appointments for a set period of time. The purpose of the contract is to prevent transplant noncompliance and consequently waste from occurring. According to various AH transplant professionals, the patient needs to show commitment to the transplant by self-improvement via compliance. Those patients who show improved compliance behavior are then placed onto the waiting list or their hold status transforms into an activated status on the waiting list. The process of testing a patient and evaluating the outcome of it is best described by Dr. Benton and a transplant nephrologist, Dr. Ingel respectively:

“We also look at their history of compliance with regard to their dialysis treatments. If the person has a history of missing 3 out every 5 or 6 treatments, for example, you know they’re not going to take their medications. A person

like that we'll bring in and we'll let them know that 'your track record to date suggests that you're noncompliant' and we may be able to show them documentation or letters from their nephrologists stating as such, and we'll indicate to them that we will complete their evaluation but not activate their name on the list until we see an improvement in their behavior. Some of them we never hear from again, they accept the fact that they are just noncompliant, and that's OK. For others, that becomes the lever, if you will, to make them straighten out their lifestyle. And when we get documentation that they're going to dialysis as they are supposed to, then we will put them on the list."

Dr. Ingel explained how he makes a deal with patients who have a history of noncompliant behavior as a test to determine if they should be put on the waiting list:

"For example, if someone says, 'OK I know I've not shown up for dialysis and hey, I mean, sometimes I don't feel like coming in for dialysis,' I tell them that 'if we're going to put you on the transplant waiting list there's certain criteria for medical follow up that *I have to feel comfortable* that you're going to do and that may include, making all physician visits, maybe outside of the dialysis.' We might use that as a criterion, even though the person misses 25% of their dialysis treatments. If they make 90% of their clinic visits, *I might accept that as a sign of compliance*. So *I'll sometimes be flexible in that*. If however, we work this out and say, 'OK you'll have to make your clinic visits,' and they don't do that either, I think what I might do is talk to that person, and say, 'you can't make clinic visits, therefore I personally don't think you should be on the transplant list'" (emphasis added).

As these excerpts show, the test of compliance relies on objective data (e.g., whether or not a patient shows up for dialysis). However, the interpretation of the objective data is made according to subjective and arbitrary standards. That is, the clinician assesses whether the patient has demonstrated sufficient compliance behavior based on the duration and type of compliance performed. Dr. Ingel gave greater weight to one form of compliance behavior than to another to justify wait-listing a patient. Like other aspects of the decision-making process for wait-listing patients, the test of patients' compliance is individualized. There is no set protocol that the team uses to standardize assessments of compliance. The following cases illustrate the types of patient noncompliance that transplant professionals evaluate and how they go about addressing it.

- Dr. Benton: Michael Walker, 32 year old, had a stroke but I'm not sure if it was a stroke or seizure. He's a Jehovah's Witness. I told him in a kidney transplant one rarely loses blood and requires a transfusion. But if he wants a pancreas, it may require a transfusion, but he doesn't want a transfusion, he's a hard core. I'd do it if he has a hematocrit of 30 or 40 but it's not there yet. He's a healthy young kid, no diabetic symptomatology.
- Dr. Julian: He smokes marijuana.
- Dr. Benton: Yeah, I drink cabernet.
- Lorna: But drinking is legal.
- Dr. Julian: He needs to go through quarterly review.
- David: He's the first person I've interviewed who I feel shaky about-- I'm afraid of his compliance, it's like shooting craps.
- Dr. Benton: Any evidence?

David: He misses meetings.  
 Rose: Always a good excuse.  
 Lorna: That's even more worrisome.  
 Dr. Julian: I'm not so sure if that's a sign. I mean does he miss dialysis-- that's more objective.  
 Dr. Benton: I agree with Ken [Dr. Julian] -- Let's get a hold of the patient records and get a feel from them. If there's a problem let's bring him to the table.

This case illustrates how in the face of uncertainty in defining noncompliance, the team relies on putatively objective measures of it. Toward the end of the discussion, the team seeks objective measures of the patient's noncompliance behavior and concludes with the need to reassess the patient after further examination of noncompliance. Members of the team were cautious about giving a transplant to someone who may not comply. Interestingly, the surgeon discounts the patient's use of marijuana as a problem that would hold them back from wait-listing the patient. The following case illustrates the relationship between compliance and finances.

Rose: Her brother lost a kidney from not taking his medicines.  
 Dr. Ingel: The main concern is, I'm still not sure of her financial options for paying for medicines.  
 Dr. Benton: If she doesn't have money to pay for the meds, we can't do it.  
 Dr. Julian: She's totally naive... I think she'd be a disaster.  
 Dr. Ingel: She doesn't have the financial wherewithal. She just didn't show up. Maybe it was financially motivated.  
 Rose: She's incredibly manipulative in terms of appointments.  
 Dr. Julian: She only showed up in four out of twelve appointments. Elisa,<sup>162</sup> you're going to have to help us out!  
 Dr. Benton: [To Rose:] Write in the letter that we can't activate your name with unresolved financial issues and a track record of noncompliance. If those can be corrected, we will reconsider.  
 [Discussion of how Dr. Easton, a nephrologist, perceives not listing people without financial coverage as a problem.]  
 Rose: So put her on hold?  
 Dr. Benton: Put her on hold-- give her a year on hold. See if her track record improves, if her compliance becomes stellar.

This case is a good example of how noncompliance forestalls patients from getting actively listed for a transplant. The team places such patients on hold until they can prove their responsibility for maintaining a kidney. By using the hold status, the team temporarily acts as a

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<sup>162</sup> Knowing that I have some formal training in bioethics, Dr. Julian occasionally asked for my advice. However, I did not provide any feedback during the meetings. Outside of the meetings I offered my opinion when asked. On several occasions Dr. Benton explained certain issues directly to me during the context of the meeting so that I would be able to understand what was going on.

gatekeeper to transplant access. By the time a patient's history of noncompliance arrives at the transplant center, it is not necessarily distinguished in terms of valid problems (financial) versus a patient's motivated noncompliance, but the team tries to at least understand its cause. Since it is difficult to determine whether the cause of a patient's noncompliant behavior is voluntary or involuntary,<sup>163</sup> the transplant team is willing to give patients a chance to get a transplant, which is in keeping with the general philosophy of the center. This case also shows that noncompliance *per se* is usually not sufficient to forestall wait-listing. In sum, the team generally does not prevent noncompliant patients from getting wait listed, unless there are other mitigating circumstances and/or patients have demonstrated after several chances, that they would not be capable of maintaining a kidney.

#### Transplant professionals' attitudes about noncompliant patients

Briefly portraying transplant professionals' personal attitudes about noncompliant patients is helpful to reveal the difficulty in evaluating such patients because they raise serious concerns and frustrations. There is a view shared by a few members of the transplant team that noncompliant patients are irresponsible and thus are like children. For example, the transplant secretary, Rose, mentioned how tired she is of calling patients to find out why they missed their appointments with the transplant physician by stating: "I'm sick of being a mother hen to these people." In a similar vein, when asked how she felt about noncompliant patients, Kathy, a transplant coordinator asserted:

"Well, I feel that people are adults, and they should make adult decisions, and I'm not here to be the transplant police. So when a person doesn't get their labs drawn, I may tell the secretary to call so and so, but after a while, I feel that they need to take responsibility themselves as adults. But if you keep hounding someone, then you're treating them like a child."

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<sup>163</sup> See Chapter 8 for the distinction.

Initially, Dr. Benton was angry when patients were noncompliant and consequently lost their kidney. As he grew older, noncompliance bothered him less because he “know[s] it’s going to happen.” In addition, he noted, “Noncompliance in my mind is something that’s between you and your organ. If you blow it, I’m not going to get angry about it.” Another transplant surgeon, Dr. Riley, related his views of noncompliant patients to wasting scarce resources:

“I become very concerned. We always discuss with the nephrologist, and sometimes the dialysis nurses who are taking care of these patients, the severity of their compliance. If we are significantly concerned, we’ll discuss the situation with the patient to alert them that their persistent lack of compliance with coming to dialysis, which is the most difficult thing, could hinder them from getting a transplant. And as such, we could then go the next step, and if they continue to persist in their behavior, take them off the list. Because we have a limited resource of organs and we do everything we can to be fair and equitable and no one feels that there is any fairness in a patient with normal abuse of behavior that has been treated and then counseled and everything else, persists in that kind of behavior, then we give them a vital organ or limited organ, or someone else may stay on dialysis for another eight years or even die on dialysis, only to have them abuse the organ and lose it because they are noncompliant. It’s not ethical in our books, so we require the patients to develop that compliant relationship.”

These comments suggest that fairness in kidney allocation is best achieved when irresponsible patients are prevented from getting listed and competing for a kidney.<sup>164</sup>

#### Patients’ noncompliance and request for a second kidney

Transplant professionals have stronger attitudes about giving patients a second kidney when they were noncompliant with the first one and thus caused its rejection. If such patients desire a second kidney, AH is willing to perform a living (related) donor transplantation but not necessarily list them for a cadaver donor without serious reevaluation.

Transplant professionals determine noncompliance with a kidney transplant according to similar criteria used to determine noncompliance with dialysis. Specifically, they frequently check patients’ blood chemistries to see if they have been taking immunosuppressant

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<sup>164</sup> Some dialysis and transplant professionals share the view that patients sometimes “sabotage” their kidney through noncompliance with taking immunosuppressant medications. Professionals believe that patients may “forget” to take their medications because they are isolated with a transplantation, and wish to return to dialysis because it offers patients greater social support. Social support is manifested through contacts with other patients, and with technicians and nurses who attend their needs three days a week and wait on patients while they are getting dialyzed.

medications, and check to see if patients have been attending their post-transplant clinic appointments. Dr. Benton explained how he identifies noteworthy forms of transplant noncompliance:

"I don't think that missing an occasional dose of medication is a big deal because it happens to everybody. And I tell my patients that 'if you miss a couple doses of your drug don't panic, don't worry about [it], nothing bad is going to happen.' But I think a person who habitually misses doses every now and then, or misses more than say 2 or 3 days in a row of their medication is definitely noncompliant. The person who misses office visits on a routine basis, again, an occasional miss, an occasional missed office visit, or an occasional missed lab test is understandable. But if it becomes a routine thing where the coordinators and nurses have to call the patient, you've missed it again, then they're noncompliant."

Noncompliant transplant recipients are under even greater scrutiny because the team perceives them as already having wasted the kidney and "abusing a limited resource," as David put it. According to Nancy, the transplant team is more "cynical" and "vigilant" about patients who want a second transplant after having been noncompliant with the first one because there is an even greater chance that such patients will waste the kidney again. Nancy elaborated on this point: "When there's a question about how they lost their first graft, then we look at them a little more carefully." Some members of the AH transplant team did not think that patients who have not complied with the transplant regimen should ever get onto the list for another transplant. Because of these strong feelings, decisions about re-transplanting noncompliant transplant recipients are more difficult. Dr. Benton explained the team's approach to noncompliant patients who ask for another kidney:

"If they lose the transplant and it was clearly due to noncompliance, we will hold that as a definite bias against them for a re-transplant. They will have to somehow demonstrate that they recognize that they contributed to their own loss of the organ, and won't do it again. We have never refused retransplant to anybody solely based on noncompliance, but we certainly have used that as one of the factors to turn [down] patients for a retransplant. As an example, I can tell you we have two examples that come to mind that were both tragic but we stuck to our guns. One [of the two examples] was a young girl of 15 who got her mother's kidney. As was expected, as a teenager she was not compliant, lost her mother's kidney, went back on dialysis, wanted to be retransplanted at the age of 17 and we refused. We said, 'come back and see us when you're 20 or 21 when you're an adult, and have a track record of compliance.' She came back, we put her on the cadaver list, this is 4 to 5 years later, she got a cadaver kidney within a year and was noncompliant with the medications again and lost that kidney. Wanted a third kidney and we said absolutely not. You're a dialysis patient for the rest of your life, or until something new with immunosuppression technique is available where you don't have to take the pills. And we stuck to that."

Even in the case of noncompliant patients, we see that the team continues to give patients several chances to get another transplant. Thus, there is still some leniency.

Besides the concern about wasting kidneys by giving them to noncompliant patients, there is also an indirect financial motivation for not transplanting noncompliant patients. The motivation is to preserve graft survival rate statistics. The statistics become worse by transplanting noncompliant patients because their grafts do not survive past one year. A comment made by Dr. Benton in response to one case further illustrates the team's attitudes about patients who present risks to the transplant center's statistics: "It screws our graft survival statistics. We're great at one year but [we're] below [the] three to five year rate because of the high social risk group we follow." Insurance companies tend not to have contracts with transplant centers with poor statistics. Without the support of insurance reimbursement, transplant centers would have to shut down. This issue does not apply as much for the case of high risk patients such as highly sensitized patients, and patients with diabetes and with heart problems. Insurance companies are supportive of transplant centers that have good one year statistics and transplant high risk patients, since these factors demonstrate broader transplant capabilities than centers which transplant only pristine patients.

### **Constructions of Patients' Motivation and Ambivalence**

During patient selection meetings transplant professionals often raised the issue of whether or not patients were motivated or ambivalent about getting a transplant. During interviews transplant professionals never explicitly listed ambivalence or lack of motivation as a barrier to getting wait-listed. However, they spoke about these issues in the selection meetings as important considerations in the evaluation process. Having picked up from evaluation meetings that motivation was a theme, the head surgeon was asked about his interpretation of the

importance of motivation. After explaining its importance, he then noted that he never uses the word motivation.<sup>165</sup> It appears that this concept is sometimes somewhat below the transplant professionals' conscious surface yet it definitely emerges in discussions during evaluation meetings. Let us now examine transplant professionals' perceptions about motivation and ambivalence and how these issues factor into their decision-making process.

Dr. Benton defined "motivation" in a way that accounts for the diversity of patients' manners of expression:

"The way I define motivation is, a person who I believe truly understands the potential pitfalls and still says, 'doc I want it.' And I think as long as I get that statement from a patient regardless of whether they're cheer leading while they're doing it or being very stoic and quiet, I'm happy with it. I don't want the personality to get in the way."

Why is it important for patients to be motivated and not be ambivalent about getting a transplant? The shared understanding is that being motivated leads to better transplant outcomes.

Motivation is important to David, a transplant social worker, "because [it has] a lot to do in recovery." Dr. Benton explained why he believes patient motivation is necessary:

"I think a patient has to be motivated to get a transplant because a transplant is not like going in and getting your gall bladder out or getting your appendix out. It is an operation so it's similar in that regard, and I'm using a surgical comparison because it does entail an operation. But getting a transplant has so many potential complications, and has a rigorous compliance requirement. I think that the patient who's motivated, who really wants the transplant, and wants to have the outcome that transplant may give them, has a better chance to deal with the hardship that may come along with the transplant. I think that's probably the primary reason why we look for someone who is motivated. We all know that getting a transplant, while it can be very easy for some patients, it's probably not very easy for most. There are some problems."

Dr. Riley, another transplant surgeon, noted the connection between patient motivation and transplant outcome by relating it to patient compliance:

"...It's always good to have a motivated person to work with because it gives you a sense of confidence that the outcome is going to be better and there's going to be less hindrance on the outcome because of patient factors. [EG: Patient factors being...?] Compliance, diligence with their health care maintenance, their observations of their sense of well-being, their vital signs monitoring and those kinds of factors. Patients have a lot of control over things that can happen to them and their reports of what happens to them to us."

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<sup>165</sup> This reflects the advantage of participant observation in which subconscious thoughts surface that would otherwise be difficult to explicitly discuss during interviews.



Clearly, motivated patients have better outcomes because they are more likely to be compliant and not waste a kidney.<sup>166</sup>

Conversely, the transplant team is cautious about ambivalent patients because the center has a history, which they often allude to, of transplanting ambivalent patients who had poor clinical outcomes and adverse psychosocial responses to the outcomes. Such patients had complained that they should not have done the transplant in the first place. Nancy revealed why Dr. Benton is cautious about transplanting ambivalent patients:

"But if a person was adamant and said no [to turn down a kidney offer], Dr. Benton is really one for never trying to talk a patient into a transplant if they don't want to do it. He said that is a bad way to start. You're starting off on the wrong foot. And any time something happens that doesn't go exactly right, this person is going to say, 'See, I told you, I didn't want this.' And he will never do that... You *have to want* this transplant in order for him to do it" (emphasis in original).

The history of transplanting ambivalent patients has grown into somewhat mythic proportions because evaluations of such patients elicit strong reactions in transplant professionals. Notably, transplant professionals often make begrudging references to past "problem patients." The following two case discussions exemplify how the team deals with ambivalent patients:

- Dr. Benton: JJ. Cardiovascular risk.  
Dr. Julian: JJ is a she. [gets up to retrieve the medical record from Dr. Benton]  
Dr. Benton: I saw her in February and she was still ambivalent.  
Dr. Julian: She said she was scared of the surgery. She had undergone mammogram, [she does not have] cancer but [it] had to be resolved. This patient told us she didn't want a kidney transplant. She's 59 or 60.  
Dr. Benton: She's got to shit or get off the pot. She's marginal and she's got to tell us why she wants a transplant and be motivated and be her own advocate. If she's ambivalent, and we're ambivalent, [it's not good]. I'll write her a letter.  
Dr. Julian: I remember she told us she wanted to take her off the list. She's not on the list.  
Dr. Benton: We've had transplant patients who've been ambivalent and they've only been sorry. After the surgery they wonder, 'why does this and that go wrong?'  
Dr. Benton: [quotes one displeased kidney recipient as saying] 'take out my kidney!'  
Dr. Julian: [mentions how another ambivalent patient complained of having diarrhea ever since the transplant.]

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<sup>166</sup> It is possible that expressing motivation is "good" because it corresponds with a related culturally valued personality characteristic of being assertive. In the US, assertiveness is prized over passivity. This value may be due to the norm for people to associate these qualities with male and strength versus female and weakness, respectively (see Lutz 1990).

This case reveals the transplant team's discomfort and ambivalence about transplanting patients who themselves are ambivalent. While the team hopes to give a transplant to anyone who is eligible and sincerely wants one, they are struggling with the impulse to not transplant patients who exhibit ambivalence. The team deals with this uncertainty about transplanting ambivalent patients by mimicking them and recollecting how past ambivalent patients were complainers and thus not worthwhile transplanting. Ultimately, in JJ's case, Dr. Benton wrote a letter to JJ to ask her to clarify whether she was actually interested in getting a transplant. This action thus provides the patient a chance to still get a transplant rather than being automatically removed from consideration. Consider the following case:

- Dr. Benton: 68 year old male. Very ambivalent at the time about wanting a transplant. Not yet on dialysis.  
David: I thought he was very ambivalent also.  
Dr. Benton: If we list him, only offer him a perfect match. There are 5-10 perfect matches a year. Medically he's OK, but wait for John and Ken [Drs. Ingel and Julian].  
[Comment about there not being little written about the patient by the other social worker, George. He had written that the motivation for the transplant was the doctor's referral. The patient's memory was questionable.]  
Dr. Benton: Table him until Medical [evaluation with transplant nephrologist]. List him only if he comes forward enthusiastically. If we list him it will be a mistake.

Again, the transplant team does not want to entirely prevent patients from getting a transplant because they exhibit ambivalence. As a compromise, Dr. Benton, taking age into consideration, was willing to transplant the patient in the case of a perfect match (6 antigen match). Since perfect matches lead to few side-effects and other complications, the patient is thus less likely to complain and respond poorly to the transplant should a problem arise.

Given that motivation is important to assess, the question that arises is: How do transplant professionals determine if patients are motivated or ambivalent? All of their explanations indicated that there was no objective or set method for making the determination. The important point here is that transplant professionals make decisions about wait-listing patients by relying on subjective assessments of the cultural value of motivation. The team relies

on two ways of assessing motivation. First, some transplant professionals ask patients questions that would provide a telling response. Specifically, they ask patients, “Why do you want to get a kidney transplant?” According to George, a transplant social worker, knowing why patients want a transplant is important because:

“I think it’s a barometer, a barometer of their interest in supporting and maintaining a transplant once they’ve got it. It’s a clue, a cue ... I think interest, enthusiasm, desire are good barometers of how much they will value a transplant and take care of it.”

A red flag is raised in the minds of transplant professionals when patients reply to the above question with “My doctor told me to get tested” because this reflects the patient’s lack of personal determination to get a transplant. Yet such a response may, in fact, be a sign of faith or trust in the physician. Physician bioethicists contend that trust in the physician is an essential feature of the healing relationship between patients and physicians (Brody 1992; Cassell 1991). Numerous studies report that many patients in the US rely on physicians to make treatment decisions on their behalf because of their trust (Cassileth, et al., 1980; Penman, et al., 1984; Strull, et al., 1984; Ende, et al., 1989; Degner and Sloan 1992). Transplant professionals might be therefore confusing the lack of motivation with patients’ trust in the physician.

Nancy, a transplant coordinator, recounted how she realized a patient was ambivalent about getting a transplant when an older woman said, “My family said I should do this.” Nancy then asked the patient, “Well what do you think?” and the patient responded, “Well, I don’t know, if they think it’s the best, then I’ll do it.” David, a transplant social worker, noted that people who are not motivated will tell him, “Well, what if this doesn’t work, and I don’t know, and I’m a little afraid,” whereas people show motivation when they say, “Hey, I’m ready to go today, show me the operating table.” These comments suggest that transplant professionals are

cautious and at transplant meetings, less enthusiastically advocate placement on the waiting list of patients who express fears about experiencing adverse effects from transplantation.

Members of the transplant culture appear to share a view that certain personality types are better transplant candidates than others. Notable is the value placed on proactive patients. During the meetings, transplant professionals occasionally made positive comments about candidates who had made a big effort to secure a transplant.<sup>167</sup> Those who are not proactive in their search for a kidney transplant may not receive as positive a review. For example, members of the team sometimes remarked that a marginal patient was taking too long a time to get through the evaluation process as a sign that the patient was not an ideal candidate.

The second way transplant professionals assess motivation level is by relying on their interpersonal interactions with the patient. Most commonly, transplant professionals pick up on a patient's "vibes" in response to the questions they ask. David asserted that the difference between motivated and unmotivated patients is clear: "You pick up on it. And people that are ambivalent, they'll show." A transplant coordinator, Jennifer, likewise said that she picks up the "vibes" from patients if they are not so interested in a transplant, based on what they say about the reason why they are seeking a transplant. In addition, she pointed out that ambivalent patients often raise questions that reflect doubts in a patient's mind about having a transplant. For example, there are patients who know unsuccessful transplant recipients, and ask, "How do I know it's going to work for me, can you guarantee me?" Regarding this question, Jennifer said:

"I think if you're generally a person who's looking for a 100% guarantee, we can't do that, so they might shy away from it a little more. We'll find there are some people who, it seems by their questions, are looking for a reason not to get a kidney transplant."

Jennifer related other questions that patients ask that indicate their ambivalence:

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<sup>167</sup> For example, the team admired the tenacity a man who lived out of town who stayed at the closest hotel/dorm so that he could meet with the transplant nephrologist first thing in the morning.

“What if this isn’t successful, then what are you going to do?”

“I know so many people who did just fine on dialysis, how can you explain that?”

“Are the side-effects of the medications going to cause me a lot of damage, just as bad as dialysis would?”

Jennifer concluded: “I mean in some ways those are reasonable questions too, but you kind of walk into the room sometimes and you just know when the person’s, I don’t know how to explain it, [sigh] you just get a vibe.”

Kathy, another transplant coordinator, reported that it is difficult to assess whether patients are motivated because the information session lasts only an hour. However, she can tell if someone is motivated when they: a) ask many questions in order to obtain as much information as they can, b) show interest in what is being said, and c) are attentive. Nancy explained in greater detail the process of assessing patients’ motivation: “Well, first I ask them how they arrived at that decision, first of all, to be transplanted. And then if they ask some questions during the interview, or if they look interested at least, you know.” She acknowledged the fact that some people do not express much enthusiasm because they came directly from dialysis and are tired. Nancy also said that she will then “probe around” by asking questions to see whether there is a medical reason for patients’ being tired or whether it is due to boredom or disinterest. She related that motivation is “just the idea of they’re being enthusiastic about their really wanting to do this. If they sound indifferent, we would ask them, you know, is this something you really want to do?” Nancy concluded that there is no established way she makes her assessments of patients’ enthusiasm, but rather “you sort of go on generalities, and just kind of the feeling that you get.”

Transplant professionals perceive patients’ motivations as indicative of their future compliance with their transplant. Those who show high levels of motivation are likely going to

be more compliant with taking their immunosuppressants and therefore be more likely to have a successful outcome. By being cautious about ambivalent patients, transplant professionals may help patients make better decisions about whether or not to get a transplant and thus ensure that transplants go to those who are most seriously interested in it. These practices can be considered utilitarian because they seek to maximize the greatest good of a kidney and minimize the chance of harm to kidneys by only transplanting motivated and compliant patients.

### **Turn Downs**

Occasionally, the transplant team reviews patients on the waiting list because they have turned down kidney offers. Recall that in Chapter 8, patients turn down kidney offers primarily because of fear and uncertainty. The team might consider such patients ambivalent. As discussed in Chapter 8, the team removes patients from the transplant list for turning down several kidney offers. This practice can be seen as a mechanism for removing ambivalent patients from the waiting list. The team's approach to patients who turn down kidneys is to warn them, usually in writing, of the consequences of turning down kidneys. The following cases demonstrate how the transplant team dealt with two such patients.

- Dr. Benton: Ken Delaney, age 60. This is the guy who's missed his appointments. He's turn down a couple, he's afraid.  
Lorna: He was Hepatitis C positive.  
Dr. Benton: My recommendation is the next turn down, he's off [the list]. [Tells Rose:] Send him a letter. [Dictates:] You've turned down several kidneys before and we need to know if you wish to remain on the list. If you stay and turn down another, we'll take you off the list.
- Dr. Benton: Pam Donahue. Is she active?  
Rose: K or KP, whichever comes up first.  
Dr. Benton: When did we activate her?  
Rose: She waffles... I told her if she keeps turning them down [they'd remove her from the list].

In both cases, the team has already given patients at least one or two opportunities to get a transplant and turn it down. Dr. Benton gives them yet another chance, but with an ultimatum. In the first case we see that Dr. Benton's letter warns Ken D. that turning down kidneys is

considered a problem by the transplant team. It is the patient's responsibility then to inform the team of his intentions to either stay on the list or remove himself. Thus, warning patients reinforces the value and need for patients to make up their mind and stick with a course of action. In the second case, the patient is seen as ambivalent since "she waffles" in her decision about accepting an offered kidney. Removing such patients from the list serves as a form of safeguarding the team from future encounters with ambivalent patients. Put in another way, the team engages in a process of eliminating marginal patients. In summary, we have seen how the team can repudiate from further evaluation those patients who fail to uphold the values of motivation and personal responsibility.

### **Finances**

This section examines the role of patient finances on the transplant team's decision-making process for wait-listing patients. It considers the transplant team's responses to two different situations: 1) when patients do not have insurance coverage for transplantation; and 2) when patients desire multiple listings at AH. The main point of this section is that patients' financial situation influences, albeit rarely, the team's decisions about wait-listing them. Specifically, the transplant team will not transplant patients who do not have Medicare and have not applied for Medicaid. This policy is in place not because the transplant center will not get paid, but rather because such patients will be unable to purchase their medications necessary to maintain the kidney transplant. Before presenting cases of each situation, this section examines the team's attitudes about the impact of finances on the transplant center activities and their methods of evaluating patients' financial situations.

As part of the transplant evaluation process, the social workers help patients identify their insurance or co-payment schedules. This information must be figured out before a transplant.

Transplant social workers currently have been getting increasing pressure from their institutions to be more forthright with patients about the costs of immunosuppressant drugs and insurance. For example, social workers handed out information forms to wait-listed patients attending the mandatory annual review meeting which state the following about Medicaid financial support:

"It is VERY IMPORTANT to know if you are on spenddown [a deductible] in order to plan for your transplant. IF YOU CANNOT AFFORD TO PAY FOR YOUR SPENDDOWN, HAVING A TRANSPLANT MAY NOT WORK FOR YOU. There is little the transplant staff can do to help you with your spenddown" (emphasis in original).

This statement clearly conveys the importance of patients having sufficient funds to manage a transplant, and acknowledges that transplantation may not be feasible. Dr. Benton explained why the examination of patients' financial situation is becoming increasingly necessary:

"What we don't do and what we should do, and I think most centers are guilty of this, at least many are, and in our center we are guilty, is we don't look very carefully at their financial status. We never have. We've never refused transplantation here to anybody because of financial status. But it is becoming clear that this is a big problem with compliance, if you can't afford your medications, you're not buying them. And I guess that one could possibly argue that people who clearly are very severely financially disadvantaged probably shouldn't get a transplant, because they're not going to take their medicines. While, we're not doing that at the moment, I think this is becoming an issue."

The surgeon's comment suggests that the lack of financial support may evolve into a category used by the transplant team for the process of eliminating those patients least 'fit' to maintain a kidney. George, a transplant social worker, noted that the team does not allow patients to wait to determine their financial capacity to afford a transplant after it occurs, since many have said in the past, "I'll just figure it out after the transplant" and eventually had financial problems maintaining the kidney. George has a reputation among the team members for being very direct about the costs of immunosuppressant medications with patients. He explained what he tells patients who are not able to cover the costs of the medicines:

"What I recommend to them is several things. First of all, I don't think I'm cruel, but I'm very direct. I do not think I do anybody any good to mince any words about this. I don't think it's fair to them, and it's certainly not fair to me. [tapping hand on table to emphasize points:] I don't want one person walking out of this room thinking that 'they'll find me a way. If I get the transplant, they'll find me a way.' And I tell them, 'we cannot find you a way. This is your responsibility. Know this before you go into it.' [end tapping] And I pretty much say it just exactly like that. Now some people think that's not very nice, I know they don't... But they just got to understand what they're taking



themselves in for [unclear], they're trading one set of problems for another set of problems. [taping:] And I can guarantee you within a period of time, that other set of problems will be just as pressure laden as the [last] problem."

Although it is important for patients to figure out their finances, members of the transplant team report that they have never refused to wait-list patients for a kidney because of the lack of funds. However, the following case shows that in practice, the team actually may not wait-list patients because of financial limits.

- Dr. Benton: 37-year-old woman with diabetes for 26 years. No cardiovascular disease history. Small woman, 130 lbs. She wants a KP, no medical problems. Do you recall any psychosocial issues, David [social worker]?
- David: Nothing blatant but she'll need additional support from the team. Her overall understanding is slow, cognitive impairment, weak information recall. Although she goes to dialysis she doesn't go to other appointments. She forgets to do things.
- Dr. Benton: Does she live alone?
- David: With her mother. The patient has a 14 year old learning disabled son.
- Dr. Benton: If she's qualified for Medicare we'll do a transplant. She has to make an effort to get it. Then we'll put her on the list. There's a big difference with reimbursement with Medicare. I don't see a reason and Medicaid to say no. Put her on hold until David tells us what her financial situation is. If she can't get Medicare the hell with her. It's a test of compliance, frankly. I have a problem that she's eligible for Medicare and can't get her act together to get it. That's a problem.

This case shows how the transplant team is concerned that the patient does not have any insurance to cover the operation. While almost all kidney transplant patients are covered by Medicare, those who seek a kidney-pancreas transplant must obtain additional insurance to cover the pancreas part of the surgery, which often includes applying for Medicaid. In addition, Dr. Benton explained that they will not transplant this patient if she cannot manage to go through the necessary steps of obtaining coverage. Since Medicare coverage is offered to almost everyone seeking a kidney transplant, there is little reason for the patient to not receive it already. If the patient is simply not assertive enough to seek coverage, the team will dismiss her case because she lacks motivation. By this token, the team places the onus of decision making to transplant the patient on the patient's personal responsibility to seek coverage for her health care. In other words, the team makes the association between the patient's personal responsibility to "get her

act together” financially with the likelihood of compliance with taking immunosuppressant medications. In this way, the team relies on the value of personal responsibility as an objective criterion for keeping such patients on or off the waiting list.

The following case presents a situation in which the patient has sufficient funds but her request for a transplant threatens the financial well-being of the transplant center. Instead of choosing only one transplant center for wait-listing, some patients (only 1%-2%) seek listing at multiple transplant centers. This is called “multiple listing.” Multiple listing increases the chances of being offered a kidney. The ethical dilemmas of multiple listing are introduced in the case below:

Dr. Benton: Mary Kent, KP listed at [name of another transplant center].  
Lorna: She wants to be double listed.  
Dr. Benton: I don't know her, 46 year old. Dr. Riley is usually very positive but he says she's an elderly looking woman.  
Lorna: Most centers charge a listing fee if they are multiple listing. I think it's fair \$346. Same for one or two organs. It's UNOS policy to charge the transplant center for the fee, but it is not policy for the second transplant center to charge the patient, even though most are doing that now.  
Dr. Benton: We still lose out on a deal if our primary has gotten a transplant at their second center. A lot of people at UNOS are against multiple listing.  
Lorna: It's not UNOS's business.  
Dr. Julian: It's discrimination to poor people.  
Lorna: But that's life.  
Dr. Ingel: Not everyone has insurance.  
Dr. Benton: Only 2% of wait-listed patients are double listed.  
Dr. Ingel: When I saw her I was concerned with her vascularity.  
Dr. Benton: [looks at chart. Since he never saw this patient, he was trying to figure out what to do with her.] How long has she been on the list at [the other center]?  
Rose: One month.  
Dr. Benton: Probably OK from vascular view, we've done worse than this.

Several issues are raised by this case. First, we see how socioeconomic issues are woven into transplant committee's discussions of patients. The discussion was not limited to medical contraindications to transplantation, but also addressed ethical dilemmas about multiple listing (see Miller 1992), (which were, however, peripheral to the decision about wait-listing the patient). It is generally expensive for patients to get multiple listed because of the costs incurred

in travel and time away from work, and even the listing fee at the second transplant center. The ethical quandary is that wealthier patients are better able than poor patients to get listed at multiple centers. This financial inequality directly contradicts the philosophy inherent in UNOS' organ allocation system which prohibits the practice of 'buying organs' as well as the value of equal access to care by all patients regardless of ability to pay.

This case also raises another ethical issue of the transplant center looking out for its own interests compared to the patient's interests. Specifically, Medicare and Medicaid do not reimburse the listing fee to transplant centers where patients have come to be listed secondarily. Thus, when patients are listed at AH as the second transplant center, AH may lose resources unless the patient pays for the second listing fee. The head transplant coordinator recommended this practice as a policy.

Lastly, Dr. Benton made an assessment about the patient's clinical suitability for a transplant by comparison to other patients in similar situations. This comparative practice has been shown to occur at other transplant centers (Surman and Purtilo 1992). Dr. Benton concluded another case similarly: "He's a sick diabetic but we've seen others like him so I don't see any problem." It is a conservative form of decision making based on casuistry.<sup>168</sup>

Multiple listing is a contentious topic because it is a means of beating the current system of allocating scarce resources by being put into many different candidate pools. Only those financially secure can afford to do this. The problematic issue is that the wealthy are more likely to receive scarce resources. It is especially in the context of scarcity that advantages by wealth are seen by UNOS, policy makers, and the public as problematic. Consider how people frequently seek second medical opinions, yet there is little debate about this action. While

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<sup>168</sup> Casuistry is a form of case-based analysis whereby decisions about a current case are extrapolated from comparison to a similar case resolved in the past (see Jonsen and Toulmin 1988).

limiting multiple listing would constitute a violation of patient's autonomy, allowing multiple listing seems to violate the utilitarian mode of allocating scarce kidneys (Mason and Corbett 1997). Despite the fact that multiple listing is uncommon, it has generated much tension by transplant policy makers and even lead New York State to ban multiple listing altogether (Miller 1992).

### **Foreign Nationals**

The last issue the team considers when deciding to wait-list patients pertains to their citizen status. Citizen status may act as a barrier to (either foreign or American) patients gaining access to a kidney transplant, depending on perspective. According to UNOS policy, transplant centers are allowed to transplant up to 5% of their yearly volume on foreign patients (both resident aliens and foreigners) (UNOS 1997f). While kidney patients in the US pay for the transplant surgery through Medicare, Medicaid, or both, foreigners pay by cash up front.<sup>169</sup> The financial incentive to transplant many foreign patients constitutes one reason why there is a 5% cap.

The main reason for limiting the number of foreigners who transplant centers are allowed to transplant (via cadaver donors) is that 'they' take a limited resource away from Americans (Office of the Inspector General 1986; Davis 1993). An organ that goes to a foreigner is one less organ that goes to an American. Some opponents feel that Americans should get kidneys first, some argue this simply because of being American, or because Americans pay taxes (Protas 1986; Jonasson 1986). In the context of limited resources (kidneys) worldwide, Americans (and other countries) become fraught with xenophobic and/or racist feelings.<sup>170</sup> The tensions over

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<sup>169</sup> While the transplant center and surgeon receive the entire payment for transplant services from foreigners, they only receive a small portion of the bill from reimbursements by Medicare and even less by Medicaid.

<sup>170</sup> Such xenophobic feelings are consistent with the restrictions placed on non-citizens from working in the US

transplanting foreigners and the 5% cap are indicative of the American value of taking care of “their own” first.

Transplant centers have become responsive to negatively-toned media reports of foreign nationals receiving US kidneys. During the course of fieldwork, the AH transplant team was confronted by two cases of foreign patients who sought their services. Yet AH turned one patient down despite a legal framework that permitted his transplantation. This situation is important because it shows how the media played a significant role in formulating the transplant team’s decisions. AH limited their willingness to transplant foreign nationals due to such negative media accounts to avoid local public outcry and lowered donation rates. The following is an in-depth case analysis of how historical, political, and economic forces influenced the transplant team’s decision making about two different foreign patients. Before presenting the case of the rejected foreign candidate, let us first review how the media deals with issues of transplantation. After presenting the case of the “rejected” foreign national, it is then compared to the case of the foreign patient who was accepted for wait-listing at AH.

#### The media on transplanting foreigners

In May 1985, *The Pittsburgh Press* released the first of a series of articles demonstrating conclusively that the Presbyterian-University Hospital had been denying kidneys to Americans and providing them to foreigners instead (Schneider and Flaherty 1985). It was this exposé that prompted the OIG to conduct a study on the access of foreign nationals to US cadaver organs (Office of Inspector General 1986).

More recently, and more pressing, in the spring of 1997, word got out to the media -- initially to the local (and only daily) newspaper and then subsequently to the Sunday evening

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(personal communication, Laura Siminoff).

television news show 60 Minutes -- that The Cleveland Clinic engaged in a test protocol of preparing brain-injured patients for organ donation in a way that many people considered ethically questionable and amounted to homicide under Ohio law (Funk and Mazzolini 1997; Wendling, et al., 1997). The protocol under scrutiny entailed first taking brain-injured patients off life-support (ventilator) and then administering two drugs -- Heparin and Regitine -- to maintain organ suitability for transplantation. Heparin stops blood from clotting, and Regitine is a vasodilator and increases blood flow to the organs and consequently reduces blood pressure. The protocol has been used since 1967 at various other hospitals.

It is standard medical practice to test the occurrence of death using equipment such as an electronic heart monitor to ensure that a patient's heart had stopped beating for at least two minutes. In addition, physicians who are not involved in the organ procurement process are responsible for declaring death. Critics of the protocol, however, believed that The Cleveland Clinic tested death by the lack of a carotid pulse. Critics also believed that the drugs used reduce blood pressure, thereby hastening death to the extent that it "kills" the patient. Yet the director of health affairs (a physician) at The Cleveland Clinic argued that the dose of these drugs was insufficient to kill a patient. Bioethicist Tom Tomlinson noted that physicians engage in practices that hasten death all the time, including removing a patient from a ventilator and administering morphine. While the Cuyahoga County prosecutor's office required that the Cleveland Clinic halt its protocol, its representatives maintained that their protocol did not constitute homicide. It is not the goal here to discuss the politics involved between The Cleveland Clinic and the Cuyahoga County prosecutor's office. Rather it is important to show the effects on the local transplant community of the media's report of The Cleveland Clinic's protocol.

The transplant community throughout the US expressed alarm by the news, not because they believed The Cleveland Clinic's protocol constituted homicide, but for another reason. They feared that the media's expansive and one-sided reporting of The Cleveland Clinic's practices would cause people to think twice about letting dying family members become potential cadaveric donors or even about signing their own driver's license to be a donor in the future. As discussed at the end of Chapter 3, the transplant community is highly protective of the transplant establishment and fears that misinformation will adversely effect organ donation.

Fortunately, based on personal communication with the local OPO representatives and members of The Cleveland Clinic's transplant department, the incident had relatively little effect on The Cleveland Clinic's and AH's transplant frequency in the following months. That is, organ donation continued at a stable rate after the media outbreak. However, a few patients in this study expressed concern that The Cleveland Clinic's protocol was unethical. Now let's turn to the actual case.

### Case analysis

The patient, who we'll call Vittorio Moreno, is an Italian man who originally sought a kidney transplant in Italy, however, the waiting lists were extremely long. Italy has the lowest rate of organ donation in Western Europe (Land and Cohen 1992). Although Vittorio's family offered to donate to him, Vittorio declined their offers and went to other European countries to become listed at their centers, but was rejected. Subsequently, Vittorio learned from his nephrologist (who's brother works at AH), that AH would be willing to evaluate him for a transplant. Vittorio came from Italy to the AH transplant center and was evaluated by the transplant team.

Dr. Benton: This is the guy from Italy. His nephrologist is in Italy. Ken [Dr. Julian] knows Dr. Lombardo [the Italian nephrologist]. Sarah Burke [the hospital CEO] doesn't want to transplant anymore

foreigners. People [foreigners] already on the list we'll keep on [the list]. It's an ethical issue since we called him over -- should we list him? In the US, most families try to get a living-donor and this guy doesn't want to take from his family even though his family is willing. Is it ethical to do it? [Mentioned how the local newspaper, *The Plain Dealer*, will find out].

[There was talk among the group of 'taking care of one's own,' and that Americans will be upset to learn about transplanting a foreigner with American organs in times of shortage.]

Lorna: We're not obligated because he came here.

Dr. Benton: We have to be careful because *The Plain Dealer* is looking for new stories. There is no problem with transplanting foreigners with live donors. [He mentioned how he should 'aggressively market' doing living-donor transplants with foreigners, having them use this facility.] The Sheik had brought a live-donor for his transplant at CMC the other day.

[The team chuckled about the donor being really a voluntary 'donor' or someone the Sheik coerced into doing it. This was a common rumor. It was not said explicitly, but that was definitely the tone of the words said about the Sheik's LRD].

Dr. Benton: In Italy nobody donates. European countries are clamping down on Italy because they don't donate. Other centers in Europe already turned him down. Sarah said we're not supposed to do it. [Dr. Julian talks about being against doing foreigner transplants]. [Dr. Benton mentioned having transplanted an Italian patient 3-4 years ago who had AB blood. He felt 'comfortable to do it ethically' because there is no shortage of AB donors. He mentioned having done a half dozen foreign transplants.] But this guy is blood type O.

[The committee all said, 'Oh!' because blood type O is most common and thus many people compete for it.]

Lorna: My vote is no.

Dr. Benton: I agree. I'm sorry he had to spend all that money coming here [even though AH is under the 5% foreign UNOS limit. I told the Italian patient that there has been a political change in the last 3 months] (regarding his talk with Sarah). I had told Sarah that doing a foreign transplant is not a Medical Director decision but a hospital decision so I told her to decide on the policy and she said 'No' against doing foreign transplants.

Here we see that Dr. Benton is reluctant to transplant Vittorio Moreno primarily because of the fear that the public will learn, through the media, about AH transplanting foreigners with American kidneys and thus stop donating organs. During this selection meeting I asked Dr. Benton "but don't you think *The Plain Dealer* could do a story on this anytime since it's happening all the time?" He agreed but noted that this would be another chance for it to happen. There would be tremendous backlash if the newspapers learned of many foreign transplants being done especially because of the financial incentives. Most Americans would be upset that patients could pay cash to get a transplant to get a kidney which goes against federal law established in 1984 by NOTA.

Although AH is below the 5% cap on foreign transplants, Dr. Benton is cautious of the media, given the recent events at The Cleveland Clinic, in 'exposing' transplant practices that the



public might dislike and thus lose trust in the transplant establishment. Dr. Benton was especially leery of the *Plain Dealer's* very poor reporting and muckraking style of The Cleveland Clinic's protocol of preparing brain-injured donors. The end result would be lowered organ donation rates. A 1986 report on The Access of Foreign Nationals to US Cadaver Organs indicated that:

"Organ donation in the U.S. rests on a fragile foundation. People donate organs with the assumption that the system for distributing them will be a fair one. When they learn that foreign nationals receive organs instead of U.S. residents and that they generally do so in a shorter period of time, they begin to question the fairness of that system and may very well become less inclined to donate. Indeed, in some communities where there has been much publicity about foreign nationals receiving transplanted kidneys, there has been a subsequent reduction in donation levels" (Office of Inspector General 1986:10).

Yet during this deliberation Dr. Benton raised the fact that he has been willing to transplant other Italian patients in the past. This was because such patients had a less common blood type, AB, for which more organs are available, and thus did not threaten the pool of scarce blood type O organs. The team concluded not to list Vittorio because Dr. Benton spoke to the president of AH and received the directive to not transplant any more foreign patients, except those already on the transplant list. There is no written policy but she told him over the telephone. Although the team as a whole voted against transplanting Vittorio, Dr. Benton morally deliberated on the ethics of telling him the team would be willing to list him and then reneging the offer after Vittorio had used up many resources to come to the US for this evaluation. Because Dr. Benton had not resolved this ethical quandary, the case came to the selection meeting the following month for further evaluation.

- Dr. Benton: Vittorio Moreno. [He's] Medically perfectly OK. [I] Subsequently talked to Sarah, who instructed me not to transplant any foreign people. I brought it up with her because of more requests for foreign transplants. I told her I'm not going to [figure out the policy on it.]
- David: The question is National policy.
- Dr. Benton: [We] can do up to 5% of the list but there's no mandate to do foreign transplants.
- Lorna: This guy wants a cadaver-donor kidney even though he has a living-donor.
- Dr. Benton: I felt this was a CEO position. Personally I don't feel comfortable. I can't justify doing them [with] 30,000 Americans on the list. I wouldn't know how to justify it to *The Plain Dealer*. Are we obliged to do a transplant for him because he spent all this money before we made a decision?

Sarah-- are you prepared for *The Plain Dealers*' next expose is foreign transplants. That's the only downside. When Americans are dying on the list.

Dr. Julian: My conscience tells me we should put him on.

[Dr. Benton concurs]

Lorna: I have a problem because he has other family members willing to be evaluated (his daughter). That bothers me.

Dr. Benton: I agree with Ken [Dr. Julian]. I'd feel uncomfortable if we didn't list him after he made the trip and spent money.

Dr. Benton: [defends himself by saying, This is] strongly debated at UNOS. America has always shown the rest of the world how to do medicine as a gesture of citizenship... I don't feel comfortable [to not list him] when we told him to come. I agree to put him on the list, but this is the last one.

Again, we hear in this meeting concerns about *The Plain Dealer* possibly doing an exposé on AH for transplanting a foreigner, even though legally, it is permitted. In addition, the head transplant coordinator presents her concern that the team not transplant Vittorio because he already has a living donor offer and so the team should not 'waste' scarce American kidneys on him. Dr. Benton's moral conscience as well as that of Dr. Julian lead them to list Vittorio because they had originally welcomed him. Dr. Benton justifies his position by recourse to another American value -- humanitarianism and good will towards others in the world (see Davis 1993). In other words, according to Dr. Benton, the US holds a tradition of allowing people to come to the US for the best of care.

To get an even better understanding of the complexities of the team's deliberations over transplanting foreigners, let us consider the case of Fatima which came to the selection meeting the following month. Fatima is a young Malaysian college student on scholarship to study in the US. In contrast to the case of Vittorio, the transplant team was in favor of transplanting Fatima. The discussion about Fatima's case was quickly resolved by Dr. Benton as soon as her name came up, as the following excerpt from the meeting shows:

Dr. Benton: [I know we decided to not do foreign transplants, but...] This woman lives here full time, as long as her government pays for it, put her on the list. She's not manipulating the system. She's here studying and happened to be here and got sick. She's not here because she heard from the national grapevine to come here.

The distinction between the two cases lies in the fact that Fatima is a foreigner who happened to be living in the US and became sick during her stay. In contrast, foreigners like Vittorio, come to the US specifically to get a transplant. Apparently, residence in the US makes a difference because resident aliens live here via a visa, pay American taxes, and while living here ‘paying their dues.’ Foreigners who come here for the sole purpose of getting a kidney and leaving are seen by transplant professionals as “manipulating the system.” In an interview with Dr. Benton after both cases had been evaluated, he said that as a transplant surgeon, he is in favor of doing foreign transplants. But as an American citizen, he felt that organs should go to Americans first. The subtext of his comment pertains to the desire of wealth by allowing foreigners to “buy” their transplant.

### **Conclusion**

Having examined the transplant team’s decision-making process about wait-listing marginal patients, we can now make several thematic conclusions. The five key points that will be discussed below are that: a) the decision-making process was cultural, b) the *evaluation* of marginal patients was utilitarian, c) the actual *decisions* were more egalitarian than utilitarian, d) the utilitarian approach to evaluating patients was based on cultural values of objectivity, and e) the discrepancy between discussion and decision (theory and practice) can be explained by interpreting the patient selection process as a ritual.

### **The decision-making process is a multi-level cultural process**

The above examination of contraindications to transplantation reveals that several values found in different cultural domains inform the transplant team’s decisions about wait-listing patients. These domains of culture, from most confined to broadly defined, include, the culture

of transplantation, the culture of biomedicine, and American culture. The following analysis addresses these cultural domains in turn.

The strongest value pervading most, if not all, discussions at selection meetings was to not “waste” a scarce kidney by allowing very marginal patients to be wait-listed. Many of the team’s decisions involved the process of elimination. That is, the team sought to eliminate from consideration the most unsuitable patients for transplantation. The underlying question that seemed to mediate the team’s decision-making process was, “Who can we prevent from getting on the list?” The team did not necessarily want to prevent people from getting a transplant. Rather, the priority was with facilitating the ease of wait-listing patients by having eliminated from consideration those who, for reasons of noncompliance, ambivalence, lack of personal responsibility, and perhaps financial reasons, were less likely to successfully benefit from kidney transplantation. As the team carefully deliberated about each case, most team members strove to safeguard scarce kidneys from those patients who present medical and psychosocial risks of kidney rejection or death. By this token, transplant professionals’ decision-making process was characteristically utilitarian. The value to not waste organs for transplantation is found within the culture of transplantation, as shown by these data and the literature on other types of organ transplants.

Another key moral value shared by members of the transplant team is for patients to maintain personal responsibility for their own health. As shown in the previous chapter, nephrologists also held the value of personal responsibility for health as it related to compliance behavior, which suggests that, rather than being the result of specialized medical training, this value permeates both the culture of biomedicine and US culture. In fact, nine of the ten transplant professionals were of European descent (four of whom were of a Protestant

denomination, five were Catholic and one was Jewish), suggesting that their moral values correspond with the “referential” concept of self, found throughout the theory and practice of biomedicine. It is important to point out that the implication of this value on patient access to transplantation is similar to that described in the previous chapter. That is, that those patients who maintain a concept of self different from the Northern European concept ascribed to by many healthcare professionals may face difficulty being taken seriously as a motivated transplant candidate. Notably, those patients who maintain a Mediterranean-type of self concept may find little impetus to resolve a problem, e.g., drug use, since what healthcare professionals may see as resolvable problems are seen by such patients as intrinsic parts of themselves. To briefly illustrate, the team recently (and unanimously) decided to not list an African American man because despite several attempts to get him to sign the contract<sup>171</sup> to stop his cocaine use, he reported to the team that he simply enjoyed using cocaine and did not want to stop taking it.

Personal responsibility for the maintenance of the transplanted kidney is important because it is seen as a key means of preventing waste of kidneys. The issue of personal responsibility primarily arose in the cases of drug use and noncompliance because those are behaviors believed to be under a patient’s control. To throw into relief the cultural foundation of this value, we can ask the following question: We do not hold people accountable in other situations, so why do we in times of scarcity? (Atterbury 1996:274). It would be absurd for doctors to provide medical care, e.g., surgical staples, gynecological exams, chemotherapy, or appendectomies, to only those patients who have exhibited a past history of compliance. But in times of scarcity, there are many patients who equally qualify for a health care resource, e.g., the

<sup>171</sup> It is very risky to perform a major operation on someone with cocaine in their system; because of its adverse interaction with anesthesia, patients may not awake from the surgery. It may have also been the case that this patient, like other African American patients, was reluctant to sign a contract. One articulate African American male patient in this study noted that because of their oral- rather than written-based culture, African Americans tend to resist signing contracts.

kidney. Since patients are not equally responsible for their health or taking care of kidneys, the transplant team, in effect, maintains their own form of personal responsibility through upholding the role of “prudent stewardship” to safeguard scarce resources and prevent patients from wasting kidneys, as Dr. Benton stated.

Dr. Benton explained that the team’s decision to safeguard kidneys by not transplanting marginal patients is based on three main factors: 1) to protect patients and families from the “disservice of false hope” of improved health post-transplant, 2) to protect the source of organs -- the public might stop donating if it learns of kidney “waste,” and 3) to protect transplant center statistics. Employing personal responsibility as a selection criterion therefore constitutes a utilitarian approach to transplant candidate selection in its emphasis on maximizing the safety of scarce transplanted kidneys.

Another major factor affecting the team’s decisions is the consideration of the impact of wait-listing and transplanting marginal patients on transplant center statistics. The basis for protecting transplant center statistics is to safeguard its accreditation, ability to attract potential candidates, or reimbursement from insurance companies. Competition is good for business and helps to optimize the outcome of transplantation. Clearly, American economic practices influence how the team makes treatment decisions. The concern with protecting center statistics pervaded many of the discussions about contraindications above. Occasionally, this concern outweighed the risks involved in transplanting marginal patients and resulted in decisions in favor of protecting the transplant center. The need to protect transplant center statistics thus influences the choice of patients the team is willing to wait-list. This practice occurs at other transplant centers, and as other investigators noted,

“The limited availability of organs for transplantation, the morbidity associated with the waiting period, and the motivation for transplant centers to maintain good outcome statistics make it desirable to select candidates who are

likely to be medically compliant and whose health status offers the best long-term prognosis. Thus, operationally, individuals with multisystem disease, those from lower socioeconomic groups, older patients, and those with psychiatric impairment are less attractive to transplant centers” (Surman and Purtilo 1992:203).

While other transplant centers evaluate marginal patients using the same criteria, they have been shown to place differential weight on them (Holley, et al., 1998; Ramos, et al., 1994; Surman and Purtilo 1992; Soucie, et al., 1992; Schweizer, et al., 1990). It has been suggested that such heterogeneity reflects a lack of equity in the selection process (Majeske 1996). The heterogeneity can also be interpreted as the product of the influence of the aforementioned cultural values on selection decisions.

The evaluation of marginal patients was utilitarian while decisions were primarily egalitarian

In the above examination of the contraindications to transplantation we have seen that the transplant team *discusses* and *evaluates* marginal patients in a highly utilitarian way. Their decision-making process is utilitarian because the transplant team seeks to maximize the greatest good to the most people from a limited resource by wait-listing those patients most likely to benefit from it. This finding may not be surprising given that the report of the US Task Force on Organ Transplantation (1986) advocated using medical success in outcome and degree of medical need as primary considerations in determining eligibility criteria. Moreover, utilitarian approaches to allocating scarce health care resources are not uncommon (Lowe, et al., 1995), and moral judgments supporting utilitarian approaches have been found among clinicians (Foster and McLellan 1997) and the public (Bowling 1996; Furnham and Briggs 1993). On a grander scale, both utilitarianism and egalitarianism have been noted as US cultural values (Veatch 1991; Luchok, et al. 1991; Lanken, et al., 1997). US culture views individuals as inherently valuable and having equal social worth (Lanken, et al., 1997).

The *discussion* was utilitarian because the team consistently evaluated patients' candidacy in light of material principles (as discussed in Chapter 4) and cultural values (noted above) relating to the patient's potential *medical* outcome. The transplant team implicitly alluded to a combination of material principles during the selection meetings, including those within the medical, sociomedical, and personal groupings. Specifically, the concerns about medical problems, age, and obesity can be categorized under the medical material principle because of their direct effect on medical benefit, the likelihood of benefit, the length of benefit, and less so, the quality of benefit. The concerns about age, psychiatric problems, and social support fall under the sociomedical material principle. Lastly, the concerns about patients' noncompliance, ambivalence (lack of motivation), drug use, turn downs of kidney offers, and lack of finances can all be categorized under the personal material principle because they pertain to a patient's willingness and responsibility to ensure successful treatment outcome. Yet the sociomedical and the personal material principles feed back into the medical material principles, meaning that the issues raised in the former groups were discussed for the sake of resolving and securing the issues raised in the latter group.

An important finding is that the transplant team made decisions about material principles primarily according to *de jure* and *de facto* policies. The transplant center had established *de jure* policies on evaluating patients who presented with cancer, obesity, and drug use (e.g., a two or five year waiting period following cancer remission, a 300 pound maximum weight limit, sobriety required). There was little room for flexibility in decision making in these regards.

The transplant center had also established *de facto* policies or cultivated a tradition of dealing with the remaining contraindications to transplantation, notably, age, noncompliance, ambivalence, turn downs, social support, psychiatric problems, and finances. However,



measurements of these contraindications were vague, largely influenced by the values discussed above and the intricacies of individual cases. Thus clinicians used their discretion to determine the best application of the policies to individual cases.

As pointed out in Chapter 4, policies are cultural artifacts. With this anthropological perspective of policies in mind, we now face the question, Why did the team stipulate and adhere to both types of policies as opposed to only *de jure* policies? Since we can define ethics as people struggling with rules that are not written down, this behavior can be seen as a cultural practice. People follow *unwritten* rules most likely because of their worldview, moral code, or doing so may bring harmony. In the case of the transplant team, the professional worldview they shared was preventing the waste of scarce kidneys. The unwritten rules tell them how to do this in a flexible way since quantifying medical outcome and morality is difficult to do. It was within the interstices of the different types of policies, that the team practiced the art of medicine.

### Objectivity

Utilitarian criteria for selecting transplant recipients are cultural because they rely on putatively objective data to buttress their application.<sup>172</sup> Here we argue four related points: 1) that objective data are prized for cultural reasons, 2) that the choice of which objective data or standards to use is culturally based, 3) how objective data are used is culturally shaped, and 4) that the objective data themselves are culturally shaped.

First, objective data are valued in the US, and thus relied upon, because of a cultural understanding that they are without bias because they are ‘scientifically’ generated. In US culture there exists a sharp divide between objectivity and subjectivity in that the former is valued over the latter (Haraway 1991; Porter 1995). In the US, clinicians strive to be objective

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<sup>172</sup> Two interesting points are made by Porter (1995:8) who states that “Quantification is a way of making decisions without seeming to decide. Objectivity lends authority to officials who have very little of their own.”

because it is seen as scientific, medically informed, and fair, whereas being subjective is associated with emotions and weakness. Yet studies of the anthropology of science indicate that scientific studies are shaped by cultural assumptions and political motives (Harding 1993; Traweek 1993; Haraway 1991; Longino 1990). The reliance on objective data is a cultural practice since scientists find that fairness is best achieved through objective measures.

With regard to the second point about the use of objective data, the transplant team drew upon certain transplant outcome data/criteria to determine medical benefit including: “likely graft survival,” “patient survival,” and less often “quality of life” measures. “The outcome measures by which we measure ‘success’ may in themselves be influenced by our cultural biases. ‘Western’ culture places an extreme value on longevity, at times at the expense of quality of life” (Lowe, et al., 1995:357). In addition, Western medicine values mastery over death through technological intervention: “[medicine] look[s] upon death as a correctable biological deficiency,” and as a “failure” of both physicians and medicine (Callahan 1993:22; Stein 1990).

Thus, the choice of these outcome criteria is a cultural decision in that the team emphasizes graft survival over patient quality of life. Recall that the team considered a six month graft survival as an inappropriate use of scarce resources, yet some patients wished to take the risk even for such a short reprieve from dialysis.<sup>173</sup> The debate is between length of life versus quality of life from kidney transplantation. While both criteria can be said to maximize

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<sup>173</sup> It is interesting that transplant professionals’ willingness to let patients undergo risks of transplantation has decreased over time, probably in concert with technological advances. Although transplant professionals were content to transplant patients in the 1960s with a less than 40% one year cadaveric graft survival, or even in 1980 with a 60% graft survival (see Dennis 1995), it is unlikely that they would allow patients to undergo such risk when the standard for one year graft survival has increased considerably.

Dr. Benton provided a good case example in which one woman was adamant about donating a kidney to her 74-year-old father. Despite the 20-25% chance of the patient dying within the next year, Dr. Benton acknowledged that he had to respect the donor’s decision, and went ahead with the transplant. The patient died four months later. From a medical standpoint, Dr. Benton does not think it is medically worthwhile to the donor to incur the lifetime risk of living on one kidney for such little benefit accruing to the patient.

the use of the kidney in different ways, the utilitarian approach to patient selection favors length of life perhaps because it is more *quantifiable* than quality of life. Thus the idea that patients will be “most likely to benefit” from a kidney transplant by living longer rather than by living better is a reflection of our cultural preferences in treatment. It has been noted, however, that longevity or graft survival may have less relevance for effective use of the kidney than being able to live in such a way to which people are accustomed (Lowe, et al., 1995:357).

Let us now consider the point that cultural values inform how objective data are used. The objective data the team used to evaluate marginal patients can also be problematized as cultural artifacts. Objectivity is best achieved through statistics, a putatively neutral form of data.<sup>174</sup>

Statistics are the means by which policy-makers attempt to be fair to the greatest number of people, especially in a numerate society as ours (Cohen 1982). Yet we can argue that statistics are not value-free. The following comment by physician and bioethicist, Colin Atterbury, makes this clear: “rules of exclusion are ideally based on ‘objective data’ from statistical analyses. These ‘hard data’ are based on arbitrary conventions that fix the point where a result will be considered significant” (Atterbury 1996:268).

We can say that transplant professionals draw upon objective data to show that they are fair in their decision-making practices, but ultimately (and ironically) conduct subjective analyses of them. This point is best demonstrated in the case of noncompliance. The transplant team collected objective data on patients’ noncompliance behavior, e.g., the frequency of patients’

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<sup>174</sup> Whereas in popular culture, statistics are valid, empirical reflections of reality, in academics, there is a tendency for people to be more critical of statistics because of the potential to manipulate statistical data to ‘say’ what researchers want them to say. This difference in perception of statistical validity calls into question the objectivity of numbers. A case in point is that transplant quality of life studies have routinely eliminated from sample analyses the worst cases which results in a selection bias in a favorable condition (Joralemon and Fujinaga 1996). As Porter (1995:12) explains, both statistical inference and peer review are the “preeminent mechanism[s] for certifying a finding as impersonal and, in that important sense, objective.”

attendance at their clinic appointments or dialysis treatments. However, the team used subjective and even arbitrary standards to judge the meaning of these objective data. Recall in Chapter 9 that Dr. Ingel had contemplated whether “attending 85% of clinician appointments [was] *sufficient*” for a noncompliant patient to be considered compliant. Thus is it up to the clinicians to interpret the meaning of the objective data and decide whether it meets their personal standards of adequate compliance. The quantity is a mask for subjective judgment.

We turn now to the last point, that objective data themselves can be culturally-biased. Lowe and colleagues (1995:356) argue that utilitarian outcome criteria for resource allocation may embody subtle racial discrimination when there is no consideration of issues of “race,” culture, and gender in the patient population. They show that Australian physicians may discriminate against those who are poor, who are poorly compliant, and those who have inadequate access to health services. Discrimination may occur through decisions to deny medical interventions to noncompliant patients, namely, Aboriginals who are notorious for their poor compliance with immunosuppressant medications, hospitalizations, and dietary and lifestyle advice (Lowe, et al., 1995:357).

Do these observations apply to the US transplant team’s decision making? It is evident that the team considers noncompliance a reason for not wait-listing patients only as a last resort, after other contraindications have been found to be relatively risky. As we have seen in Chapter 9, medical noncompliance may be due to complex issues including differences in dietary, personal, and health beliefs. In addition, patients of lower socioeconomic backgrounds and of minority backgrounds have been shown to be most noncompliant. It is important to point out that dialysis and transplant professionals consistently perceived patients of lower socioeconomic backgrounds and of minority backgrounds to be most noncompliant. Given these trends, it is

plausible that any emphasis on noncompliance can inadvertently discriminate against already disadvantaged people. Even 37% of transplant physicians at an annual conference (n=approximately 333) agreed that using compliance criteria discriminates against minorities (Randall 1994).

#### Decisions were initially and primarily egalitarian and partially utilitarian

Despite the discourse about preventing wastage of kidneys by wait-listing marginal patients, the team generally offered patients many opportunities to become a suitable candidate and to receive a kidney beyond a strict utilitarian definition of patient selection. A strictly utilitarian approach to patient selection would prevent from wait-listing many of the noncompliant and ambivalent patients, among others who fail to demonstrate that they would “sufficiently” benefit -- that is, benefit for at least a period of a year. Instead, the team appeared to be primarily egalitarian in its practice by placing virtually all marginal patients on the waiting list. Although the team made some utilitarian decisions, these occurred after giving patients ample opportunity to become a suitable candidate (e.g., stop drug use).

In 1995, kidney transplant allocation practices were predicted to be shaped by egalitarianism because of the diversity of interests (patient, professional, public, governmental) in it (Dennis 1995). The extremely low refusal rate at AH generated by its egalitarian practices has been found to occur elsewhere. After evaluation for transplantation, most kidney programs (n=154) refused, on average: 3.0% of patients on psychosocial grounds; 7.4% of patients on medical grounds; and 0.4% of patients on financial grounds (Levenson and Olbrisch 1993). One retrospective study of renal transplant candidates excluded from transplantation found that 125 (30.6%) patients were excluded over a three year period (Holley, et al., 1998). Notably,

noncompliance, categorized as a ‘medical contraindication,’ was the reason for excluding 16 (12.8%) patients from transplantation.

What is the impetus for placing patients on the waiting list? The reasons for doing this have largely to do with the transplant center philosophy. AH is willing to transplant more marginal patients than other transplant centers, e.g., CMC, because it believes that all patients deserve a chance to get the “gift of life.” At almost every transplant meeting there was discussion of a new patient who had been turned down at CMC and was seeking a transplant at AH. CMC turned down patients primarily for cardiac problems though at least one had been turned down for noncompliance.<sup>175</sup> While transplanting marginal patients may make transplant center statistics worse, the volume of patients transplanted per year increases. A high volume is beneficial for the transplant center to maintain accreditation.

The transplant team’s actions -- talk and decisions -- reflect their cultural notion of fairness in selecting patients for the waiting list. We can argue that patients’ entitlement to kidneys is met through the transplant team’s practice of their notion of fairness. That is, while patients are entitled by law to a transplant if eligible, the team’s sense of who can be eligible relies on their notion of fairness. Fairness is a double-edged sword in its role as a tool used by the team to determine who gets onto the waiting list. The team’s notion of fairness can be summarized candidly by the phrase “two strikes and you’re out.”<sup>176</sup>

On the one hand, the transplant team is obliged by UNOS to distribute kidneys fairly. They do this by giving almost everyone a chance to get on the list to obtain a kidney. Hence, the team engages in an egalitarian manner of selecting patients for the waiting list. On the other

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<sup>175</sup> The patient who had been turned down for noncompliance at the CC was included in this study’s patient sample.

<sup>176</sup> In a different context, this notion of fairness was implicitly stated in a proposed California policy for keeping people who commit multiple misdemeanors off the streets.

hand, the transplant team expects patients to be responsible with their kidney transplant by, for instance, not using illegal drugs or being compliant with medications. Fairness in selecting transplant patients means eliminating from the list of potential candidates those patients who fail to take responsibility to become suitable candidates for kidney transplantation after being given several chances to change. In this regard, the team engages in a utilitarian mode of selecting patients for the waiting list. Fairness thus entails filtering out patients with a questionable history of personal responsibility from consideration for placement on the national waiting list.

The transplant team entertains their two notions of fairness in two temporal ways. On the one hand, the team contemplates both egalitarian and utilitarian notions of fairness contemporaneously in the context of a single meeting. Thus the team maintains fluid meanings of their notions of fairness when evaluating various patients at one occasion. On the other hand, the transplant team's notions of fairness change over time depending on the qualities of a specific patient. Each patient is first given access to the list because of the team's egalitarian notion of fairness. Yet should a given patient fail to reach established deadlines (e.g., drug rehabilitation) or uphold their responsibility, the team then switches to a utilitarian notion of fairness. This latter practice is in keeping with the team's approach to evaluating patients on an individual, case-by-case basis. The temporal element of the team's notions of fairness can be made evident further by readdressing the issue of patients reaching established deadlines. As discussed earlier in the chapter, patients are presented temporal deadlines for becoming sober and/or compliant, turning down offered kidneys, and to some extent, losing weight. The transplant team's behavior or deployment of fairness in selection practices changes over time in concert with patients' behavioral changes.

*An alternative interpretation of fairness: the “ethics of care”*

The team’s talk and decisions about patients can also be interpreted as adhering to the ethics of care. According to this standard of ethics, people make moral judgments and decisions by considering their relationship with, responsibility, and compassion for others (Beauchamp and Childress 1994:85). Partiality toward others is “the expected norm of interaction” (1994:87). For instance, a father deciding whether to donate a kidney to his daughter takes into consideration his love for his daughter as a compelling reason to donate.

Similarly, the transplant team can be seen as practicing an ethic of care for unknown patients on the waiting list who are suitable candidates of transplantation when the team expresses concern over wasting scarce kidneys by placing noncompliant marginal patients on the list. It is as if the team is safeguarding the kidneys for responsible patients from people who are deemed irresponsible. Yet their ethic of care can also be extended to marginal patients in two regards.

First, the team is especially attentive and/or sympathetic to the plight of patients who actively express their motivation to get a transplant. The team is encouraged to help (is compassionate toward) those who express much concern about getting well. The ethic of care is also made apparent by the fact that the team’s decisions were not based solely on impartial criteria. They examined each patient’s case individually to understand and attend to subtle clues about suitability for transplantation. Further proof of the team’s partiality in their decision making was their reliance on *de facto* policies. These policies were not cut and dried but were selectively drawn upon and molded to fit each patient’s situation to formulate an appropriate assessment about wait-listing. A strict reliance on *de jure* policies, by contrast, would indicate an absolute use of impartiality in decision making. Despite this different interpretation, we can see



that the team's actions according to the ethic of care correspond with those of a utilitarian approach.

#### The discrepancy between talk and actual decisions: ritual analysis

Given that AH generally wait-lists the vast majority of marginal patients, we are left wondering why the team engages in so much talk about patients with nonmedical contraindications to transplantation. We can explain their "discourse" on contraindications in psychological and functionalist ways by analyzing the selection meeting as a ritual.<sup>177</sup> Let us define rituals and observe how the selection meetings fit this definition.

Ritual can be defined as a repetitive, stereotypic collective action that is a socially and culturally acknowledged form of communication for a particular goal (Turner 1979; Pandian 1991; Tambiah 1985:126). The transplant selection meeting is a ritual in that it routinely and collectively meets to determine whether to place marginal patients on the waiting list. Ritual spaces are specially denoted areas (Turner 1992); at AH, the meetings always occurred in the conference room. Generally, the authority of those who organize the ritual is "absolute" (Turner 1979:237); likewise, Dr. Benton had the final say in decisions about listing patients.

Rituals are usually organized around typical sources of distress and/or changes in social status (e.g., funerals, illness, weddings) (Scheff 1979). Similarly, transplant meetings are distressful because evaluating patients is an emotionally and morally difficult thing to do. Notably, physicians find it emotionally and morally difficult to not help a patient who pleads for relief from a life on dialysis. According to the Hippocratic Oath, physicians are bound to help patients, not abandon them. In the US specifically, clinical aid, particularly in times of uncertainty, is expressed through action, also known as "clinical activism" (Katz 1984; Stein

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<sup>177</sup> See Katz (1981) for additional insight into the anthropological study of ritual in biomedical practice, e.g., the operating room.

1990). Thus, turning down patients for a transplant goes against the grain of a physician's professional duty. Members of the team sometimes joked to relieve tension when concluding that Dr. Benton had to write formal refusal letters to patients. The team even acknowledged that nephrologists often refer ineligible patients so that the team will spare nephrologists the pain of having to say no to them.

The crux of the answer to our question lies with interpreting ritual as a transformative performance (Csordas 1993; Schieffelin 1985; Tambiah 1985; Roseman 1991). Ritual performances are effective in transforming people's sense of self because they involve changes in individuals' symbolic meanings of their "lifeworld" (Turner 1979:64), and rhetorically by formulating meanings through social interaction in the ritual (Schieffelin 1985).

We can say that it is through participation in the transplant meetings that members of the team experienced a transformation of their moral selves. The "talk" about contraindications to transplantation, e.g., noncompliance, during the meetings can be interpreted as a means for the team to present their concerns about marginal patients getting transplanted in the context of scarcity of organs. Like the liminal phase of other rituals, the selection meeting raises much emotional and moral uncertainty and tension. In this case, the team is faced with the uncertainty of medical benefit of transplantation in marginal patients. The tension they experience during these meetings is between the discomfort of not giving patients a chance to receive a transplant or so-called "gift of life," and placing them on the list when they might reject it.

Patients who "waste" a kidney via noncompliance commit a moral transgression for not taking the scarcity dilemma seriously enough. Transplant professionals might also experience moral transgression because they have allowed marginal patients who ultimately reject their kidney to be placed on the waiting list in the first place. Such moral transgression on the part of

patients (and perhaps on the part of transplant professionals) subsequently generates emotions of frustration and anger in transplant professionals (Douglas, et al., 1996; Schweizer, et al., 1990). Transplant professionals must morally grapple with the prospect of giving organs to those who will not use them properly.

The transplant meetings are transformative in that they reset the moral world. The transplant team together engages in a process of decision making that helps resolve the ambiguity of the patient's candidacy status. The decision-making process entails doing a number of smaller activities that help make medical and thus moral sense of each patient's case. These activities include: a) presenting the patient's problem in terms of its possible implications for wasting kidneys, b) reviewing data from laboratory tests and cardiologists' letters that represent "objective" perspectives on medical and psychosocial risk-benefit ratios, and c) drawing upon national and hospital transplant policies that stipulate how to act upon certain patient dilemmas. In many cases, a medical decision is a moral decision.

It is through participation in ritual discussion of uncertain patient cases that the participants come to see decisions about patients' statuses as having a clear conclusion (see Schieffelin 1985:708). Thus engaging in discussion helps to resolve the moral tension about listing patients who might "waste" a kidney. Recontextualizing the moral uncertainties raised in each patient's case enables action to be taken in regard to them, e.g., wait-listing (see Schieffelin 1985:707).

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In this chapter we have examined how transplant professionals decide whether to place marginal patients on the national transplant waiting list. It appears that even marginal patients have access to placement on the waiting list, however, their access is hindered when they fail to

change problematic behavior (e.g., noncompliance, drug use) after being given chances to remedy their situation. Thus, the decision-making process is initially egalitarian but then transforms into a utilitarian practice to ensure that scarce kidneys are not “wasted.” Transplant centers with different philosophies, sizes, and statistics may have different approaches to evaluating marginal patients for transplantation. This chapter constitutes the last phase of analysis for this research investigation. The next chapter summarizes the study findings.

## **CHAPTER 11: CONCLUSIONS AND IMPLICATIONS OF RESEARCH**

This study has sought to examine ethnic inequalities in the access to kidney transplantation by focusing on the treatment decision-making practices of patients and healthcare professionals. Unlike other studies of transplant access, this study has taken an anthropological approach to determine whether sociocultural factors inform treatment decisions for ESRD. A cultural constructivist approach has allowed for the deconstruction of the ethnic and cultural values and beliefs underpinning treatment decisions. The present study has shown that patients and healthcare professionals make decisions about ESRD treatment that can hinder patients' access to kidney transplantation. This final chapter concludes the study by summarizing the key decisions by patients and healthcare professionals that ultimately affect some patients' access to transplantation. In addition, the chapter presents implications of these research findings for problems of access to transplantation, offers policy recommendations, and suggests avenues for future study.

### **Key Treatment Decisions**

#### **Patients**

Chapters 7 and 8 sought to examine patients' treatment decisions that inevitably formed barriers to transplant access. Three main decisions included in this category are: remaining on dialysis, and turning down offers of 1) cadaveric and 2) living (related) donors. Let us consider the findings regarding each issue in turn.

It was hypothesized that different ethnic groups make different treatment decisions for ESRD thus explaining the unequal access to transplantation by ethnicity. This study found a slight trend for more African American than European American patients to chose dialysis instead of transplantation. This finding is important in two regards. First, it may help explain

why there is a discrepancy in access to kidney transplantation between African Americans and European Americans. This is the first study to show that the patient's own choice of treatment plays a role in their access to transplantation. Second, this finding may alleviate some of African Americans' distrust of the medical establishment. The data show that "race"-based differences in access to transplantation are not entirely the result of racism on the part of the dialysis and transplant professionals, as some clinicians have proposed (see Chapter 4). With a deepened sense of trust in the medical establishment, African Americans may be more willing to donate their kidneys.

One might conclude that an increase in donations by African Americans would augment the number of kidneys available to match with potential African American recipients. However, considering the cultural construction of "race" as discussed in Chapter 4 (e.g., that genetic ancestry is not consistent within a given ethnic group), it is doubtful that more African Americans patients will receive donated kidneys. Yet without "race" and immunology in mind, we can conclude that more donations will increase the number of transplants performed overall.

Recall in Chapter 7, we considered the relationship between treatment choice and ethnicity in detail. It is worthwhile noting that other evidence suggests that a relationship between these variables exists. When controlling for sociodemographic variables that were significantly related to both treatment choice (e.g., age, religion, marital status) and ethnicity (e.g., education, religion, marital status), there was inconsistency in the significance of their relationship. The relationship between treatment choice and ethnicity remained significant when controlling for age and marital status, but it was insignificant when controlling for religion and education. This suggests that sociodemographic factors, particularly education and religion, are inextricably linked to ethnicity and treatment decisions and must be examined in all their entirety

rather than individually with regard to ESRD treatment decision making. Moreover, dialysis and transplant professionals have observed that more African Americans than European Americans preferred dialysis because they expressed fear of making changes to the unknown and enjoyed the social component of dialysis treatment. A larger sample size may show more definitively the relationship between treatment choice and ethnicity.

Two other significant sociodemographic relationships emerged with regard to treatment decisions. Patients who decided to remain on dialysis tended to be older, and separated, divorced or widowed than those who chose transplantation. It is likely that the absence of kin for the care and support necessary post-transplant influenced their decisions. The relation between age and ESRD treatment choice has been found elsewhere (Holley, et al., 1996).

The analysis of patients' decisions indicates that their choice of treatment is largely based on their perceptions of their current adjustment to dialysis and health (or what some may call "quality of life"). Freedom from being reliant on dialysis was the primary reason for seeking a transplant. This is because a lifestyle with dialysis limits or even precludes many other aspects of people's lives. In addition, patients who sought a transplant believed that it could offer even better health and a longer life.

Patients chose to remain on dialysis for several key reasons. First, patients reported that they felt relatively healthy and found no reason to alter their current health status. Supporting this view is the finding that patients would only consider a transplant if their health declined.

A second key reason patients expressed for not seeking a transplant was the concern about undergoing additional surgery involved in transplantation. Many patients reported that they needed to adjust to dialysis and heal current wounds before getting "cut on" again. Patients were trying to recover from multiple surgeries incurred from dialysis and comorbidities. In

addition, the prospect of transplant surgery raised numerous fears that the operation would: a) cause death, b) leave patients in a worse state of health than they are in currently, c) not work well and thus lead to kidney rejection, and d) lead to the need for even more surgeries. While most European Americans in this group indicated their desire to recover from prior wounds, most African Americans maintained these latter views of surgery. In particular, the lack of “guarantee” that transplantation would work prevented many patients, all African American, from seeking a transplant.

Lastly, the social component of dialysis treatment was highly influential to both con-transplant and pro-transplant patients, yet in very different ways. A main reason patients expressed for remaining on dialysis was having witnessed unsuccessful transplant recipients return to dialysis. Unsuccessful recipients constituted living proof that transplantation does not work. This finding has been noted elsewhere (Holley, et al., 1996). Interestingly, social contact among patients is common during dialysis treatment; in fact, such contact perpetuated the spread of rumors that transplantation does not work. Rumors have been found to be an especially enduring form of communication among African Americans, used to protect themselves from putative societal and medical evils (Turner 1993). In contrast, pro-transplant patients were not affected by witnessing such patients and tended to rationalize their kidney rejection. Instead, pro-transplant patients were influenced by knowing successful kidney recipients.

It is noteworthy to discuss here that most patients in this study were not hindered from seeking a transplant by having limited financial resources. That significantly more pro-transplant patients than con-transplant patients were concerned about the costs of transplantation highlights the point that finances do not necessarily prevent (con-transplant) patients from seeking a transplant. Many patients maintained that they expected to rely upon myriad resources, e.g., the



government, physicians, family, etc. for their (and their future kidney's) survival. This is important because, contrary to the expectations of Critical Medical Anthropologists, most patients continue to have access to some resources despite being unable to afford a transplant. Primarily pro-transplant patients were concerned about affording the expensive immunosuppressant medications perhaps because they would have to eventually pay for them themselves. Realistically, kidney transplantation may be a viable option only for a subgroup of eligible patients who have the financial resources to manage it after three years of government support. Patients with few financial resources are highly likely to reject their kidney when the government's support ends. Reports by transplant professionals and patients indicate that there are inequalities in the *maintenance* of the kidney transplant.

Access to transplantation must be understood as a multi-stage process. Cultural constructivism is thus best applied for understanding access at earlier stages. While structural inequalities fail to explain access to transplantation in earlier stages, they could be applied for understanding access issues, later, after the three-year period of governmental support for maintaining kidney transplants ends. However, a structural analysis may not be necessary given that Congress is in the process of changing its policies of financial support for ESRD patients. Advocates of kidney transplantation, including dialysis patients and clinicians, are currently requesting that Congress increase the duration of Medicare coverage from three years to an indefinite period of time. Expanding coverage would benefit both patients and the government since economic analysis has shown that transplantation is a more cost-effective treatment for ESRD patients than dialysis and that the net savings appear approximately four years after transplantation (Eggers 1984, 1992; Eggers and Kucken 1994).

Patients made two other decisions that substantially limited their chances of receiving a kidney transplant sooner than later, specifically, turning down actual offers of cadaveric kidneys, and refusing to accept or ask for living (related) donor kidneys. While fears of death or kidney rejection are understandably considerable factors holding people back from accepting a cadaveric kidney, they are not central to the practice of turning down living donor kidney offers. Patients declined to accept or to ask for offers of living donor kidneys because of a set of underlying assumptions relating to protecting the well-being of living donors. For instance, patients indicated that they could not ask people to donate because asking people is difficult to do, and it makes the person asked feel obligated to donate.

Many patients did not want to put people in this position by virtue of asking them to donate because of the view that organ donation should be a voluntary act. Patients also expressed reluctance to accept or ask for a LRD because of they feared risks to the donor (or the donor's family). Consequently, several patients preferred to deal with their ESRD alone. However, some patients indicated that they would ask someone to donate or accept a LRD offer only if an emergency occurred and the patient was desperate for a kidney.

In sum, patients' decisions did not coincide with what some scholars consider "rational" thought. Patients' decisions were not shaped by a "rationalized" financial cost-benefit analysis of dialysis vs. transplant in which transplantation, being the most medically- and cost-effective treatment would always be sought. Rather, patients' decisions to remain on dialysis were shaped by thought processes informed by health beliefs, personal experiences, emotions, and social conditions, notably, by personal, ethnomedical understandings about health and surgery, personal observations of other transplant recipients, and concerns over social relations in accepting and asking for living donor offers. These types of thought processes had the effect of limiting

patients' own treatment options; this occurrence has been found to occur among other decision makers (Levin 1990).

### Dialysis professionals

Healthcare professionals involved in dialysis and transplantation also made treatment choices that can be interpreted as subtle and unintentional forms of hindering patients from seeking access to transplantation. We examined two sets of decisions nephrologists routinely make about the treatment for ESRD. The first set of decisions was about when, how much, and in what ways do nephrologists convey information about treatment options to patients. The key finding was that nephrologists reported to give information about treatment options in a process over time as dictated by the biomedical cultural perspective that medical information is overwhelming to patients. Thus nephrologists can be seen as acting as a “gatekeeper” by temporarily limiting patients' access to transplantation.

In addition, dialysis clinicians or physicians did not provide life expectancy information to patients who requested it. It appears that in the fields of nephrology and dialysis, there exists a “discourse of silence” about dialysis patient mortality that is created by nephrologists' reluctance to give probabilistic information and paradoxically, reinforced by some patients who resist learning such data out of fear. If patients were made more aware of the mortality data (see Appendix V), then they might be more willing to become wait-listed so that they accrue time on the national waiting list while feeling well on dialysis. Another finding was that, despite empirical evidence showing that transplantation is a better treatment modality for ESRD than dialysis, nephrologists tended to selectively encourage patients to seek a transplant, especially those who were young.

The second set of decisions was about whether to refer patients for transplantation. Nephrologists' referral practices are shaped by factors in tension with each other. On the one hand, nephrologists' reports indicate that they adhere to federal policy requiring referral of all eligible patients to transplant centers. Further, they claimed to refer to the transplant center even patients whose eligibility for a transplant is uncertain in order to avoid introducing bias into their referral practices. These findings indicate that nephrologists do not hinder, but rather facilitate, patients' access to transplantation.

On the other hand, two problematic practices became apparent through analysis. First, while most nephrologists reported to refer noncompliant patients, they documented the noncompliance in patients' charts so that transplant professionals could more accurately evaluate them for transplantation. It was argued in Chapter 9 that such a practice constitutes a form of paternalism because noncompliance can express a form of patient autonomy. Consequently, transplant professionals' considerations of such patients for transplantation may be less than ideal due to such patients' damaged reputations conveyed through their medical charts.

The second problematic practice is that most patients who are considered ineligible for a transplant are generally not referred. The tension lies in the definition of transplant *eligibility*. There was some evidence that nephrologists construe patients' noncompliance as constituting ineligibility for transplantation. The definition of eligibility has problematic implications for referral in two regards. First, dialysis nurses do not routinely review the option of transplantation with ineligible patients as they do with eligible patients. This means that technically, medically eligible but noncompliant patients who desire a transplant do not annually receive necessary information about how to obtain one during their long term care plan reviews. Second, there is empirical evidence, albeit somewhat inconsistent, that patients of minority groups and with lower

socioeconomic backgrounds tend to be more noncompliant. This means that either a) minority patients are perceived by dialysis professionals as noncompliant more often or easily, or b) considering noncompliant patients ineligible may constitute an inadvertent form of racial discrimination.

### Transplant professionals

Transplant professionals face the decision of whether to wait-list marginal patients for transplantation. The analysis of transplant professionals' decisions suggests that their actual decisions are guided primarily by an egalitarian view of fairly allocating kidneys. That is, they tend to place most patients on the waiting list despite psychosocial and some medical contraindications to transplantation. Yet their discussion of marginal patients is largely shaped by the utilitarian values of maximizing the most good for the greatest number of people. Consequently, when there is a question about a marginal patient's ability to maintain a transplanted kidney, the team expresses reluctance to "waste" a scarce kidney. But it is only after patients demonstrate, after many chances, that they are unable to "responsibly" care for their kidney that the team decides against wait listing them.

Contrary to expectation about reasoning in biomedicine as reliant on scientific data, the transplant team's decision making was informed by cultural values and beliefs, experiential knowledge, and political and economic considerations. Their decisions were also made on a group, rather than individual, level. Specifically, cultural concerns about taking personal responsibility for one's health care permeated the discourse of scarcity. This is especially relevant given that nephrologists refer noncompliant patients to the transplant center with a note attached to their medical record pointing out their noncompliance. This practice means that patients' reputations precede them and might damage their chances of being placed on the

waiting list. Transplant professionals' decisions were also modified by their concern about maintaining good transplant center statistics which may be damaged by transplanting marginal patients, including those who do not take "proper" care of their kidneys. While the team's decision making was informed by non-normative criteria, it was also consistent with Western thought processes in its utilitarian approach of weighing the risks and benefits to best attain their goals.

The criteria kidney transplant professionals rely on to decide whether to place patients on the transplant waiting list have been shown to be used at other transplant centers (Surman and Purilo 1992; Soucie, et al., 1992; Ramos, et al., 1994; Schweizer, et al., 1990). The fact that their medical and nonmedical criteria are used elsewhere supports the generalizability of these study findings. Other kidney transplant centers have different philosophical approaches to patients and consequently allow some contraindications to transplantation to weigh more heavily on their selection decisions than others, as in the case of noncompliance (Schweizer, et al., 1990). Moreover, surveys of the public's attitudes about kidney selection specifically, and about health care resource allocation generally, have found public support of utilitarian methods of patient selection and resource allocation, particularly in light of age and personal responsibility criteria (Bowling 1996; Furnham and Briggs 1993). The results from these survey studies support the finding that utilitarian approaches to resource allocation are pervasive in Western culture. In these ways, this research study contributes to the anthropology of bioethics by uncovering the values and beliefs shaping the transplant team's ethical deliberations about placing marginal patients on the waiting list for kidney transplantation.

## **Culture of Dialysis and Transplantation**

The findings of this research investigation contribute to various fields of study within Medical Anthropology and Medicine, including medical decision making, health care policy analysis, the anthropology of biomedicine, and patient-physician communication. This research has established a baseline understanding of how American patients and clinicians view dialysis and transplantation and can thereby contribute to the growing international discourse on culture and transplantation. The comparative study of treatment choice for ESRD will increase our understanding of the medical decision-making process in general. Comparative research on treatment choice for kidney disease is fruitful not only for those interested in ESRD, but also for those seeking a cross-cultural perspective on disability, technology, and the law. “Comparative study could increase the ability of scholars and clinicians to critically examine the relationship between systems of moral reasoning and the use of medical interventions” (Levin 1990:908).

## **Policy Recommendations**

### **Education**

#### *Patients*

The results of this study can inform larger and more quantitative studies and help guide healthcare policy. The study may inform policies to educate ESRD patients and healthcare professionals about gaining access to transplantation. It is recommended that healthcare professionals educate patients more frequently about the process of obtaining a transplant. This study found that patients maintain several misconceptions about the referral process, transplantation, dialysis and rejection. For instance, patients believed that it was necessary for their physician to refer them to the transplant center instead of calling to set up an appointment themselves. It is likely to take longer to start the transplant evaluation process by waiting for a

physician's referral because patients usually visit their nephrologists once every three months. In addition, the fact that 11% of patients in this study changed their minds about treatment for ESRD requires that they obtain appropriate information about their newly made treatment choices in a timely fashion.

It is also recommended that patients are provided information about life expectancy on dialysis compared to transplantation. This is important because many patients did not know this information, although they had requested it of their healthcare providers, and such information could inform patients' treatment decisions. Evidence supporting this contention is that pro-transplant patients were motivated to get a transplant based on the understanding that patients live longer with a transplant than on dialysis. Dialysis patients should be informed that the life expectancy for ESRD will appear shorter because it includes data on patients with comorbidities and those who are clinically unsuitable for transplantation. Dialysis patients who are eligible for a transplant and for whom life expectancy data could be helpful in making a treatment choice should be informed of how to interpret the life expectancy data or else they might overestimate the dangers of remaining on dialysis. One problem that may be encountered when implementing this intervention is resistance by nephrologists. As noted above, some nephrologists were ambivalent about disclosing life expectancy data because they seek to maintain patients' hope.

#### *Health care professionals*

Nephrologists and other dialysis clinicians should be educated about two key issues. First, nephrologists should become more aware of how their communication practices can affect patients' treatment decisions. This entails giving more information about treatment options early on in a patient's illness.



A factor that may hinder this process is that clinicians wish to protect patients from scary information, such as life expectancy data, but this reactive stance may be to patients' detriment. Some patients even felt that their physicians treated them as children. As one patient, Arthur, noted, had he really understood how his diet and diabetes could cause kidney failure, he would have changed his eating habits years ago.

It is also recommended that dialysis professionals become better educated about the process of gaining access to transplantation and patients' concerns preventing them from seeking a transplant. Some dialysis professionals, e.g., nurses and technicians, indicated their lack of knowledge of the referral process. Without such knowledge, these dialysis professionals cannot accurately educate patients about their treatment options. Clinicians can also draw upon these study findings to help clarify patients' potential misconceptions about transplantation in the future. Educating healthcare practitioners about patients' cultural and ethnic patterns of thought and lifestyles related to health and ESRD may help patients make more informed treatment decisions. For instance, knowing that many patients who prefer to remain on dialysis are influenced by the fear that they will be in a worse health status post-transplant, can inform them of the survival statistics as well as other quality of life improvements in kidney transplantation. Preparing clinicians with important cultural information can therefore better enable them to offer further guidance when patients appear uncertain about treatment modalities.

#### Establish contact

Half of the con-transplant patients were influenced to not seek a transplant by knowing unsuccessful transplant recipients. Thus, another educational intervention involves having successful transplant recipients visit dialysis centers. Such contact would help dialysis patients obtain a more balanced view of transplantation since doing so would provide them living proof

of the viability of transplantation. The feasibility of such an intervention is high given that the majority of pro-transplant patients (76%) indicated willingness to remain in contact with their dialysis center should they receive a transplant.

### Policy makers

Social scientists need to inform policy makers involved in dialysis and transplantation, e.g., Medicare, physicians, of the kinds of issues and processes that lead patients from considering transplantation as a legitimate treatment. The problem is that maintaining a normative perspective of patients' treatment decisions can lead policy makers astray in their efforts to help them. By assuming that patients make normative decisions, instead of experientially based decisions, policy makers and clinicians might never address the issues that lead people away from the transplant waiting list. That is, they will be unaware of the need to help patients gain a balanced view of transplantation. They need to learn that patients' negative perspectives of transplantation are largely shaped by the ESRD culture, which is influenced by the rumor mill, lack of exposure to successful transplant patients, the patients' own cultural values, and experiential processes. In short, by not addressing patients' concerns, policy makers may maintain a system of unequal access to transplantation.

### Use of statistics

The analysis of nephrologists' education practices have several policy implications. It is obvious that American history and culture is replete with examples of the goal of equality among all people. Americans most often distribute scarce resources through utilitarian approaches (Crane 1975). To Americans, utilitarian approaches to the distribution of resources are perceived as the most 'fair' mechanism of distribution since the majority of people are likely to benefit by such a plan. Of course there are many other means of distributing goods that can be seen as fair.

To justify utilitarian approaches, American policy makers resort to the use of statistics. The US has been shown to be highly reliant on the significance of numbers or “numeracy” (Cohen 1982).

This reliance on statistics as a manifestation of utilitarianism, I argue, holds true for the allocation of kidneys for transplantation. Specifically, at the local level, that is, in the clinic, physicians apply utilitarian theory through the provision of statistical data to patients. Physicians provide statistical data to patients to justify or guide patients into seeking a given medical treatment for ESRD. This practice constitutes a manifestation of utilitarian theory because physicians decide how to maximize the greatest good of kidneys in terms of determining which patients could best benefit from a kidney transplant.

The key issue for policy makers pertains to a discrepancy in the application of utilitarianism. On the one hand, policy makers and clinicians use statistics on the local level to practice utilitarianism. On the other hand, they do not apply utilitarian theory to data on the economics of ESRD that show that maximum benefit can be attained by providing financial aid to transplant recipients longer than three years post-transplant. This discrepancy becomes clearer as we consider a major factor contributing to the complexity of this situation: many patients, despite Medicare or Medicaid coverage, do not have the financial capacity to ‘comply’ with their medicine and dietary regimens. In addition, as both the literature and this study show, the majority of such patients are minorities. As previously noted, ‘noncompliant’ patients are at greater risk for not being registered on the national waiting list. Consequently, a gap has developed between patients’ financial capacity to comply and kidney allocation policies.

Another recommendation concerning statistics is that when nephrologists present mortality statistics for transplantation and dialysis, they should caution patients about their generalizability. As one nephrologist indicated, he may tell patients the mortality rates but was

aware that patients often generalize from these statistics to themselves, which is an inappropriate way of interpreting statistical data. Most patients and people in general are unfamiliar with how to interpret statistical data. Thus, nephrologists should not only provide patients with mortality statistics on all ESRD treatment modalities, but also help patients make sense of these data.

The ethos of organ transplantation has, in recent years, been increasingly oriented to securing equality of access to transplantation by all suitable patients. For example, the point system used to allocate kidney has changed over time to emphasize equality in access. The goal then, by these policy recommendations, is not necessarily to increase the number of patients on the national transplant waiting list, but to help provide patients a fair chance at getting onto this list.

### **Recommendations for Future Research**

Since the approach of this research has been exploratory in nature, a broad range of issues have been identified which influenced patients' treatment decisions. Qualitative research that examines these issues in greater depth may prove useful in uncovering even more subtle sociocultural differences among groups of patients at different stages of the decision-making process.

Several phenomena became apparent through the course of fieldwork that would benefit from further investigation. First, an investigation of the rate in which kidney recipients visit their past dialysis center may prove fruitful for further assessing the relationship between patients' treatment decisions and knowing successful transplant recipients. There is anecdotal evidence from transplant coordinators that some kidney recipients tend to avoid contact with their old dialysis center for social and psychological reasons, e.g., feeling uncomfortable with the medical difference between themselves and dialysis patients, and fearing that such contact might 'jinx'

the newly transplanted kidney into being rejected. Even 11/46 (24%) pro-transplant patients in this study reported that they would not remain in contact. Two patients stated that they would not stay in contact because:

Talmadge: "It's not a particularly happy place. If you come in with a transplant, it's like you're lording over them, boasting."

Irving: "I don't ever want to remember I was here."

Interestingly, patients who expressed interest in maintaining contact with the dialysis center were significantly more likely to be younger (41.5 vs. 52 years) ( $t=-2.337$ ,  $p=.024$ ) and less educated (12.7 vs. 14.6 years) ( $t=-2.701$ ,  $p=.01$ ) than those who did not wish to remain in contact.

Second, a qualitative investigation of unsuccessful kidney recipients' perceptions of the causes of their kidney rejection may prove fruitful in understanding the possible nonmedical causes of kidney rejection. Transplant professionals reported anecdotal evidence that patients "sabotage" their kidneys because they missed the social support at the dialysis center. This should be examined because it could shed light on the role of financial issues in maintaining a kidney transplant.

Third, research should be conducted on the relationship between nephrologists' communication patterns and patients' socioeconomic backgrounds. Examining actual clinical encounters using a sociolinguistic approach would prove useful for delineating problems in communication that would hinder patients' access to transplantation.

Lastly, more power-neutral studies of patient noncompliance should be conducted in the dialysis population. This means investigating whether there are sociodemographic patterns among patients who engage in involuntary and voluntary forms of noncompliance. In addition, such studies should explore the practices of dietary noncompliance with an awareness of the cultural and ethnic differences in tastes of recommended food for ESRD, and patients'

perceptions of the influence of missing dialysis treatments and clinician appointments on their current and future health status. Determining whether ethnic groups engage in different forms of noncompliance (e.g., do minorities engage in involuntary noncompliance for financial reasons?) may underscore ways in which dialysis and transplant professionals can become more aware of the possibility for making healthcare decisions that inadvertently discriminate against some population groups.

### **Limitations of the Study**

There are several limitations to this study. These study results may have been susceptible to selection bias by nonrandom sampling: patients who participated in the sample may be different from those who did not participate. The data gathered were limited in generalizability to other transplant centers in urban areas and adult ESRD patients. The investigator acknowledges that using small sample sizes may not have yielded broadly generalizable data. However, many of the heuristics patients used in their decision-making process have been shown to also occur in various other studies suggesting the validity and generalizability of these study data. Further, the strength of the data collected is they described phenomena in all their complexity with consideration of context and the meaning of events and experiences for participants (Zyzanski, et al., 1992). While “quantitative correlations can describe populational patterns,” qualitative research can discover whether these factors are meaningful to health seekers and thus explain why particular decisions are made (Stoner 1985:44).

Social science methods permit the research to be data-driven, especially with regard to bodily and health-related experiences and to the natural history of illness, health, and disease experiences (Willms, et al., 1990:392). Working with a small sample thus afforded the investigator an opportunity to examine decision-making issues in greater depth than would be

possible in a large-scale survey study. This study generated data that illuminated the complexity of patients' and health care professionals' decisions and how these affect patients' access to transplantation.

## APPENDICES

Appendix I:	Patient Interviews
Appendix II:	Nephrologist Interview
Appendix III:	Transplant Professional Interview
Appendix IV:	Social Worker Interview
Appendix V:	Expected Remaining Lifetimes for US Population (1990), All ESRD Patients (1996) and Dialysis Patients (1996) by Age, “Race” and Sex
Appendix VI:	List of Dialysis Patients and Dialysis and Transplant Professionals
Appendix VII:	Categorization of Dialysis Patients’ Professional, Service, Business, and Labor Occupations



## Appendix I: Patient Interviews

### First Interview

Thank you for taking the time to speak with me today. Before we begin, do you have any questions about this interview?

What days of the week do you dialyze?

- |   |                          |        |
|---|--------------------------|--------|
| 1 | <input type="checkbox"/> | M/W/F  |
| 2 | <input type="checkbox"/> | T/TH/S |
| 8 | <input type="checkbox"/> | NR/NA  |

What time of the day do you dialyze?

\_\_\_\_ : \_\_\_\_ am / pm

- A. Why did you pick this time of the day to do your dialysis run?  
B. Why did you pick American Hospital instead of CMC for your kidney doctor?

### Part I: Life with ESRD

#### Medical History

- How did you first find out you had kidney failure?
- Did you ever have any symptoms before your kidneys failed? Yes No
- Can you describe the pain you felt?
- Did you ever have those symptoms before? Yes No
- What did you take for your symptoms?
- How long ago did your kidneys fail?
- How long after your kidneys failed did you start dialysis?
- What was the onset of your kidney failure?
  - ☐ Progressive, over a period of time -----> For how long? \_\_\_\_
  - ☐ Unexpected, all of a sudden
- What is the cause of your kidney failure?
- What do you think caused that?
- What do you think your kidneys do in your body?
- In what ways has your life changed since you started dialysis?
- How do you feel about doing dialysis?
- Are there things about the dialysis center/management/staff/patients that you:
  - ☐ Like (Specify: \_\_\_\_\_)
  - ☐ Don't Like (Specify: \_\_\_\_\_)
  - ☐ NR/NA

### Part II: Education of Treatment Options

- Who is your nephrologist or kidney doctor? \_\_Dr. \_\_\_\_\_
- Do you feel at ease with him/her? Yes No
- Can you speak freely with him/her? Yes No
- Does she/he seem to have your interests at heart? Yes No
- What do you think your options are for treating your kidney disease?
- (if not mention transplant)-- Is dialysis something you think you have to do the rest of your life?

Yes	No	D/K
-----	----	-----
- (if mention transplant)-- Has anyone has ever talked to you about transplant?

Yes	No	D/K
-----	----	-----
- (if talked re: transplant)-- Did you talk about transplants before or after starting dialysis?
- (if talked re: transplants)-- How many months after starting dialysis? \_\_\_\_
- Have you ever thought about getting a transplant? Yes No D/K
- Where did you first hear about transplantation?
- When did you first hear about transplantation?

24. Has your nephrologist ever spoken to you about transplants? Yes No D/K  
 25. Did s/he bring the subject up or did you? MD Self D/K  
 26. How much time did s/he spend talking about transplantation? \_\_\_\_\_  
 27. How many conversations did you have with him/her about transplantation? \_\_\_\_\_  
 28. Did your kidney doctor ever give his/her opinion about which treatment you should have?  
 1 ☐ Yes (What was the opinion?)  
 2 ☐ No  
 8 ☐ NR/NA  
 29. What did you think of his/her opinion?  
 30. On a scale of 1 to 5, 5 being the most encouraging, how would you rate how encouraging your kidney doctor was about you getting a kidney transplant?  
 1 ☐ Not at all encouraging  
 2 ☐  
 3 ☐ Somewhat encouraging  
 4 ☐  
 5 ☐ Very encouraging  
 8 ☐ NR/NA  
 31. Based on the way you rated your doctor's encouragement, why is it that your doctor thinks transplant is or is not a good option for you? (What did s/he say?)  
 32. Have other health care providers talked to you about transplants? Yes No D/K  
 33. How encouraging were they on a scale from 1 to 5?  
 34. What about your family, have you ever talked to them about your treatment options?  
 Yes No D/K

35. What do they want you to do to treat your kidneys?

36. Decision-Making Preference Questionnaire

*Some patients, after they have all the information they need about their illness and possible treatments, prefer to leave decisions about their treatment up to their health care provider while others prefer to participate in these decisions. Please check the statement that best describes what you believe would be ideal.*

- 1 \_\_\_\_\_ The health care provider should make the decisions using all that's known about the treatments.  
 2 \_\_\_\_\_ The health care provider should make the decisions but strongly consider my opinion.  
 3 \_\_\_\_\_ The health care provider and I should make the decision together on an equal basis.  
 4 \_\_\_\_\_ I should make the decisions, but strongly consider the doctor's opinion.  
 5 \_\_\_\_\_ I should make the decisions using all I know or learn about the treatments.

Part III: Decisions About Treatment Preferences

FOR PATIENTS REMAINING ON DIALYSIS ONLY

- 37a. Why do you not want a transplant?  
 \_\_\_\_\_ I know people who had unsuccessful transplants  
 \_\_\_\_\_ I do not want to be cut on  
 \_\_\_\_\_ I do not want to go through all the tests to get on the transplant waiting list  
 \_\_\_\_\_ I am afraid of taking transplant medications  
 \_\_\_\_\_ I am doing OK on dialysis  
 \_\_\_\_\_ I am afraid of the costs of medications  
 \_\_\_\_\_ I am concerned about not getting a kidney from a donor of my same race  
 \_\_\_\_\_ I am afraid of being worse-off from a transplant  
 \_\_\_\_\_ I am afraid for religious reasons  
 \_\_\_\_\_ I am afraid of a foreign part in my body  
 \_\_\_\_\_ I do not want to return to work  
 \_\_\_\_\_ I am afraid of death  
 37b. Have you always felt against transplantation? Yes No  
 37c. Did you ever start the process of transplant evaluation? Yes No

- 37d. Why did you stop going through transplant evaluation?  
 37e. Some patients do want a transplant because they want to get off of dialysis. What do you think about that?

#### FOR PATIENTS SEEKING TRANSPLANT ONLY

- 37a. Why do you want to get a kidney transplant?  
 37b. Did you make up your mind before or after you were told about transplants?  
 37c. How long did it take you to decide that you wanted a transplant?  
 37d. Was it hard to decide? Yes No D/K  
 37e. Some patients do not want a transplant because they don't want to 'rock the boat.' What do you think of this?  
 37f. Have you ever been referred for transplant? Yes No D/K  
 37g. Who referred you? \_\_\_\_\_  
 37h. Have you ever been called for a transplant? Yes No D/K  
 37i. What happened?  
 37j. Did you turn it down? Yes No

#### ALL PATIENTS

38. What do you think are the benefits of dialysis?  
 39. What do you think can go wrong with dialysis? (drawbacks)  
 40. What do you think are the benefits of transplantation?  
 41. What do you think are the drawbacks of transplantation?  
 42. What do you think can go wrong with transplantation?  
 43. Did any of your health care providers influence your decision?  
 1 ☐ Yes -----> Who? \_\_\_\_\_ How? \_\_\_\_\_  
 2 ☐ No  
 8 ☐ NR/NA  
 44. Did family or friends influence your decision?  
 1 ☐ Yes -----> How?  
 2 ☐ No  
 8 ☐ NR/NA  
 45. Do you have any personal values or philosophy of life that influenced your decision?  
 46. Are you concerned about the cost of transplantation? Yes No  
 47. How much do you think a transplant costs? \$ \_\_\_\_\_

#### Knowing Transplant Recipients

48. Do know people who had a transplant?  
 1 ☐ Yes  
 2 ☐ No  
 9 ☐ DON'T KNOW  
 8 ☐ NR/NA  
 49. How many people do you know who had a transplant? \_\_\_\_\_  
 50. How many of them were successful \_\_\_\_\_? unsuccessful \_\_\_\_\_?  
 51. How did you meet them?  
 52. How long have you known them?  
 53. How often, when, and where do you see them?  
 54. Are you close with them? Yes No  
 55. What kinds of things did they tell you about their transplant experience?  
 56. Were they positive or negative about it? + -  
 57. Did their experiences influence your treatment decision?  
 1 ☐ Yes  
 2 ☐ No  
 9 ☐ DON'T KNOW

- 8 ☐ NR/NA
58. Before you met patients who had a transplant, did you ever think about getting a transplant?
- 1 ☐ Yes
- 2 ☐ No
- 9 ☐ DON'T KNOW
- 8 ☐ NR/NA
59. Have any of these quality of life issues influenced your decision-making?
- 1 ☐ Independence
- 2 ☐ Food/Eating
- 3 ☐ Drinking Fluids
- 4 ☐ Social Life
- 5 ☐ Ability to Work
- 6 ☐ Ability to Travel
- 7 ☐ Energy Level
- 8 ☐ Sexual Functioning
- 9 ☐ Physical Symptoms
- 10 ☐ Appearance / Body Image
- 11 ☐ Other (Specify: \_\_\_\_\_)
- 99 ☐ DON'T KNOW
- 88 ☐ NR/NA
60. How does the idea of surgery make you feel?
61. Do you have any religious concerns as far as undergoing an operation?
62. What does your church think of kidney transplantation? D/K
63. What do you think happens to people after they die?

#### Part IV: Live-Donor vs. Cadaver-Donor: Considerations

64. Has a family member or friend offered to donate a kidney to you?
- 1 ☐ Yes
- 2 ☐ No
- 9 ☐ DON'T KNOW
- 8 ☐ NR/NA
65. What is your relationship with that person?
- |  |                                     |                                    |
|--|-------------------------------------|------------------------------------|
| 1 <input type="checkbox"/> Mother      | 5 <input type="checkbox"/> Daughter | 10 <input type="checkbox"/> Uncle  |
| 2 <input type="checkbox"/> Father      | 6 <input type="checkbox"/> Son      | 11 <input type="checkbox"/> Spouse |
| 3 <input type="checkbox"/> Sister      | 7 <input type="checkbox"/> Cousin   | 12 <input type="checkbox"/> Friend |
| 4 <input type="checkbox"/> Brother     | 9 <input type="checkbox"/> Aunt     | 13 <input type="checkbox"/> Other  |
| 99 <input type="checkbox"/> DON'T KNOW | 88 <input type="checkbox"/> NR/NA   |                                    |
66. Did they volunteer on their own to donate or did you ask them to donate?
67. How would you feel about that person donating a kidney? Would you accept it?
68. Did you expect that person to offer to donate to you?
- 1 ☐ Yes -----> Why:
- 2 ☐ No
- 9 ☐ DON'T KNOW
- 8 ☐ NR/NA
69. Do you think your relationship with this person would change after the transplant?
- 1 ☐ Yes -----> How
- 2 ☐ No
- 9 ☐ DON'T KNOW 8 ☐ NR/NA

70. Are there other family members who are healthy enough to donate but who haven't offered yet? Yes No D/K
71. How would you feel about asking them to donate?
72. What kind of donor do you prefer?
- 1 ☐ Living-Related Donor
- 2 ☐ Cadaver donor
- 9 ☐ DON'T KNOW
- 8 ☐ NR/NA
73. Do you think LR donors are Different from Cad donors? Yes No D/K
74. What kinds of personal attributes or features would you want your ideal donor to have (i.e., male, female, young, old, African American, white)?
75. Would you have different concerns if a relative vs. a friend were to donate?
- 1 ☐ Yes
- 2 ☐ No
- 9 ☐ DON'T KNOW
- 8 ☐ NR/NA
76. Who would you prefer a friend or family member?

#### Part V: Demographics

77. Respondent's sex:
- 1 ☐ Male
- 2 ☐ Female
78. How old are you?
- \_\_\_\_\_ years 8 ☐ NR
79. What is your race or ethnic heritage?
- 1 ☐ White (of European descent) (Specify: \_\_\_\_\_)
- 2 ☐ African American
- 3 ☐ Asian
- 4 ☐ Hispanic
- 5 ☐ Other (Specify: \_\_\_\_\_)
- 8 ☐ NR/NA
80. Did you grow up in this city?
- 1 ☐ Yes
- 2 ☐ No (Specify where: \_\_\_\_\_)
- 8 ☐ NR/NA
81. Do you belong to any formal religious denominations? If so, what denomination?
- 1 ☐ Catholic
- 2 ☐ Eastern Orthodox
- 3 ☐ Protestant
- ☐ Methodist
- ☐ Presbyterian
- ☐ Episcopal
- ☐ Baptist
- ☐ Other
- 4 ☐ Jewish
- ☐ Reform
- ☐ Conservative
- ☐ Orthodox
- ☐ Other
- 5 ☐ Muslim

- 6 ☐ Other
- 7 ☐ No Denomination
- 8 ☐ NR/NA
82. Do you consider yourself a religious person?
- 1 ☐ Yes
- 2 ☐ No
- 8 ☐ NR/NA
83. How important is religion in your life? Rate on a scale of 1 to 10, 10 being high:
- | 1                        | 2                        | 3                        | 4                        | 5                        | 6                        | 7                        | 8                        | 9                        | 10                       | 88                       |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
84. What do you think a very religious person is like?
- 84a Do you pray? Yes No
- 84b Do you think it does any good? Yes No
- 84c Do you go to church? Yes No
- 84d Does going to church help you live with dialysis/kidney failure? Yes No
85. What is your marital status?
- 1 ☐ Single
- 2 ☐ Living with a Partner
- 3 ☐ Married
- 4 ☐ Divorced/Separated
- 5 ☐ Widowed
- 8 ☐ NR/NA
86. What is the highest grade or level of education you completed?
- 8 ☐ NR/NA
86. Are you employed?
- 1 ☐ Yes ☐ School
- ☐ Full-Time
- ☐ Part-Time
- 2 ☐ No ☐ Due to Illness
- ☐ By Choice
- 3 ☐ Sick Leave
- 8 ☐ NR/NA
87. What is your occupation? \_\_\_\_\_
88. Please list all the people who live in your household:
- | Name     | Age | Occupation | Care Role |
|----------|-----|------------|-----------|
| 1. _____ |     |            |           |
| 2. _____ |     |            |           |
| 3. _____ |     |            |           |
| 4. _____ |     |            |           |
| 5. _____ |     |            |           |
89. Who helps you with the following chores/activities/supports:
- Food shopping/preparation/cooking: \_\_\_\_\_
- House cleaning/laundry: \_\_\_\_\_
- Takes care of you when you are ill: \_\_\_\_\_
- Takes you to your medical appointments: \_\_\_\_\_
- Provides you with emotional support: \_\_\_\_\_
90. What is your family total pre-tax income last year?
- \$ \_\_\_\_\_ 8 ☐ NR/NA
91. What city/ borough do you live in?
- 8 ☐ NR/NA
92. Do you live in a house or apartment?

93. Do you own your own home? Yes N
94. What is your zip code?
95. What is the primary cause of your renal failure?
- |    |                          |                           |
|----|--------------------------|---------------------------|
| 1  | <input type="checkbox"/> | Diabetes                  |
| 2  | <input type="checkbox"/> | Hypertension              |
| 3  | <input type="checkbox"/> | Glomerulonephritis        |
| 4  | <input type="checkbox"/> | Cystic Kidney Disease     |
| 5  | <input type="checkbox"/> | Interstitial Nephritis    |
| 6  | <input type="checkbox"/> | Obstructive Nephritis     |
| 7  | <input type="checkbox"/> | Collagen Vascular Disease |
| 8  | <input type="checkbox"/> | Malignancies              |
| 9  | <input type="checkbox"/> | Metabolic Disease         |
| 10 | <input type="checkbox"/> | Hereditary Disease        |
| 11 | <input type="checkbox"/> | Sickle Cell Disease       |
| 12 | <input type="checkbox"/> | Aids Related Disease      |
| 13 | <input type="checkbox"/> | Other (Specify: _____)    |
| 14 | <input type="checkbox"/> | Cause Unknown             |
| 88 | <input type="checkbox"/> | NR/NA                     |
96. What is the date of your first dialysis treatment?
- \_\_\_\_/\_\_\_\_/\_\_\_\_ 8 ☐ NR/NA  
month/day/year
97. How many years have you had renal failure?
- \_\_\_\_ 8 ☐ NR/NA
98. How many months have you been on dialysis?
- \_\_\_\_ 8 ☐ NR/NA
99. Who is your primary payer?
- |   |                          |                  |   |                          |                        |
|---|--------------------------|------------------|---|--------------------------|------------------------|
| 1 | <input type="checkbox"/> | Medicaid         | 4 | <input type="checkbox"/> | Commercial             |
| 2 | <input type="checkbox"/> | Medicare         | 5 | <input type="checkbox"/> | Self                   |
| 3 | <input type="checkbox"/> | Other Government | 6 | <input type="checkbox"/> | Other (Specify: _____) |
| 8 | <input type="checkbox"/> | Unknown          |   |                          |                        |

## Second Interview

It has been about 3 months since we last talked. I am interested in learning if you have made any new treatment decisions since the last interview. I will be asking you some questions about your current treatment preferences, and if and how they may have changed. Before we begin, do you have any questions about this interview?

The last time I talked to you, you had expressed [a lack of] interest in transplantation.

- ☐ Undecided about getting a transplant    ☐ In the process of transplant evaluation  
☐ Not interested in getting a transplant    ☐ On the active waiting list for a transplant

1. Do you still feel that way? (Have your views changed?)  
1    ☐ Yes    --->Why?  
2    ☐ No
2. Has anything happened or did you learn anything new to make you reconsider?  
1    ☐ Yes    --->What?  
2    ☐ No
3. Has anything happened or did you learn anything new to reinforce your decision?  
1    ☐ Yes    --->What?  
2    ☐ No
4. Hypothetically, what would it take to change your mind?
5. How do you perceive your health now? (from 1 to 10)
6. Would you feel any differently about transplantation if your health was: worse? better?
7. Would your view of transplantation be different if you saw or knew people with successful transplants?
8. What kinds of things about transplantation have you heard other patients talk about?
9. Has religion influenced your decision in any way?

### Evaluations?

10. Have you been referred yet for transplant evaluation?  
1    ☐ Yes (How long ago? \_\_\_\_/\_\_\_\_/\_\_\_\_) By Whom? \_\_\_\_\_  
2    ☐ No (Specify why not: \_\_\_\_\_)  
9    ☐ DON'T KNOW  
8    ☐ NR/NA
11. Where in the process of evaluation are you now?  
1    ☐ About to start  
3    ☐ Almost done  
2    ☐ Have started (Consultations with Clinicians)  
4    ☐ Wait-Listed  
9    ☐ DON'T KNOW  
8    ☐ NR/NA
12. Have the series of medical evaluations influenced your decisions/concerns?  
1    ☐ Yes -----> How: \_\_\_\_\_  
2    ☐ No  
8    ☐ NR/NA

### Pro-Transplant Patients

13. If you were called to get a transplant tomorrow, would you accept it?
14. Have you recently been called to get a CAD transplant?  
1    ☐ Yes    -----> What happened? -----> Turn it down/Someone else got it  
2    ☐ No



8      ☐      NR/NA

LRD vs. CAD

15. Since we last spoke, (3)/(6) months ago, have any more family or friends offered to donate?  
1      ☐      Yes      -----> Who?  
2      ☐      No  
8      ☐      NR/NA
16. Were any people who got tested, a match?  
1      ☐      Yes      -----> Who?  
2      ☐      No  
8      ☐      NR/NA
17. Do you have any family members who have not yet offered to donate?  
1      ☐      Yes  
2      ☐      No
18. How would you describe your relationship with those who did offer compared to those who did not offer?
19. If no one had yet ever offered to donate to you, would you have asked your family or friends to donate? Why/Not?

Knowing TX Recipients

20. Do you know of anyone who received a transplant in the last 3-6 months?  
1      ☐      Yes  
2      ☐      No  
8      ☐      NR/NA
- How many people \_\_\_\_\_  
How many were successful \_\_\_\_\_ unsuccessful \_\_\_\_\_  
How did you meet them?  
What kinds of things did they tell you about their kidney transplant experiences?  
Were they positive or negative about it?  
Did they influence your decision about transplantation? ----->      Yes / No

Education

21. When you first got sick, do you wish you had been given more information about transplantation?  
22. How about now, do you wish you had more information about transplantation?  
23. How often does your doctor, nurse, social worker ask you if you want a transplant?  
24. Who talked to you the most about transplantation as a treatment option?

Explanatory Models - I'm interested in how you understand your body and health:

Function

25. Can you list other parts inside of us that are related to kidney disease?  
26. What do each of these parts do?/function?  
27. Where did you learn about how kidneys function?

Personality

28. Has your kidney disease ever affected your personality or behavior?  
Did anyone else ever think you were acting differently because of your kidney failure?  
29. How do you think would you feel having someone else's kidney inside of you?

Time

30. Do you think your kidneys will ever get better? \_\_\_\_\_  
31. How many years do you think people can live on dialysis? \_\_\_\_\_  
32. How many years do you think people can live with a transplant? \_\_\_\_\_  
33. What would be the minimum number of years of successful functioning for a transplant to be worthwhile going through? \_\_\_\_\_

### Measurement

- 34. Do you know how your kidney function is measured?
- 35. How do you know if your kidney function is getting worse?
- 36. Do you call your kidney failure by a certain name when talking about it with friends?

### Females

- 37. How do you feel not having your menstrual period?

### Causality

- 38. Do you think that kidney failure can be caused by imbalance or impurity in blood?
- 39. Do you think high blood pressure and hypertension are different?
- 40. Do you think that kidney disease can be caused by supernatural forces, sinning or other people's ill will towards someone?
- 41. A lot of people believe in fate, that things are meant to happen. Do you think your kidney failure was meant to happen?

### Pain or Discomfort

- 42. Are you ever in pain or discomfort from your kidney disease?
- 43. What do you do to relieve your pain/discomfort?
- 44. Does that usually relieve your pain/discomfort?
- 45. If not, what do you do then?

### Alternative Medicines/Healing

- 46. What else besides dialysis and taking prescribed medicines are you doing to improve your health or manage discomfort?
- 47. Do you do any kind of alternative healing or medicine, spiritual healing? (e.g., herbal teas, yoga, go to faith healer, use roots, magic)
- 48. If nothing, how would you feel about taking alternative medicines for improving your health?
- 49. What kinds of alternative/spiritual healing do you do/use?
- 50. How did you find out about it? Who told you about it?
- 51. Where do you get medicines or meet the person?
- 52. How do you think alternative medicines/practices interact with standard medicine?
- 53. Do you think alternative medicines/practices work together, separately, or supplementally with standard medicine? Explain how:
- 54. Do you think alternative medicine is more, less, or equally effective as standard medicine?
- 55. Would you continue using alternative medicine when you get a kidney transplant?
- 56. Have you or will you change(d) the types and amounts of alternative medicines you use over time?

### Missing Treatments

- 57. Have you ever missed your dialysis treatments?
- 58. Why did you miss the treatments?
- 59. Do you usually reschedule a missed treatment?
- 60. How do you physically feel when you miss your treatments?
- 61. Does the dialysis staff ever call you when you miss dialysis?
- 62. How does the staff react to you or say to you when you return from a missed day?
- 63. How does that make you feel?
- 64. What do you think your doctor or the transplant team feels about you missing treatments?

### Third Interview

I am interested in learning if you have made any new treatment decisions since the last interview. The last time I talked to you, you had expressed [a lack of] interest in transplantation.

- ☐ Undecided about getting a transplant      ☐ In the process of transplant evaluation  
☐ Not interested in getting a transplant      ☐ On the active waiting list for a transplant

Do you still feel that way? (Have your views changed?)

- 1      ☐      Yes      (If status 2, ask for update)  
2      ☐      No

If YES (Did Not Change Mind):

Has anything happened or did you learn anything new to reinforce your decision?

- 1      ☐      Yes  
2      ☐      No

If NO (Did Change Mind):

What happened to make you change your mind?

Have you talked to your doctor about your new decision? Yes / No How have you acted upon it?

#### ALL Con-Tx Patients

What do you imagine happening to you in the future if you had a transplant?

#### ALL Pro-Tx Patients

Have you recently been called to get a CAD transplant?

- 1      ☐      Yes      -----> What happened? ----->  
   Turn it down / Someone else got it  
2      ☐      No

How do you think the transplant will affect your life?

Do you think you will maintain contact with the dialysis center after you get your transplant?

- 1      ☐      Yes      -----> Why?  
2      ☐      No      -----> Why?  
8      ☐      NR/NA

\*\*\*

### NONCOMPLIANCE QUESTIONS

I know that patients often have better judgment of what their medical needs are than doctors or nurses do. I've talked to a lot of patients who've done things that doctors call noncompliant. I'd like to ask if you've ever had similar experiences, and so you know, I'm not going to tell anyone about anything you say.

1. Has a doctor or nurse ever told you that you were noncompliant?  
Yes /No What happened?
2. Has a nurse or doctor ever told you that you were noncompliant but they were wrong?  
Yes / No What happened?

#### Medication

3. Have you ever been unable to take your medicines because you did not have enough money to buy them? Yes / No  
For how long were you unable to buy your medicines? \_\_\_\_\_  
Did you change the way you took your medicines before you ran out of them? (stretch/time)  
Yes / No  
Did you ever tell anyone (HCP/kin) about not being able to afford your medicines? Yes / No
4. Have you ever taken your medicines at different times than the doctor tells you to?  
Yes / No Why?  
How did or would it make you feel to take the medicines at the prescribed time?  
How does it make you feel to take the medicines at the time you prefer?
5. Have you ever taken different amounts of medicine than the doctor tells you to?  
Yes / No Why?  
How did or would it make you feel to take the amount of medicines the MD prescribed?  
How does it make you feel to take the amount of medicines that you prefer?

#### Dialysis Treatment

6. Have you ever missed any of your dialysis treatments?  
Yes / No Why? What happened? Do you remember what you did that day instead?

#### Dietary Regimen

7. Have you ever eaten foods or drinks that you knew you should not have?  
Yes / No Why?  
How did it make you feel to do that at that moment?  
How often do you do that?
8. Have you ever not eaten specific foods that you were supposed to eat?  
Yes / No Why?  
How did it make you feel to not eat them?  
How often do you do that?

## Appendix II: Nephrologist Interview

### Referral for Transplantation

1. What medical and psychosocial criteria do you consider to determine whether a patient is suitable to be evaluated for transplantation?
2. What factors prevent you from referring patients?
3. Are there certain kinds of patients for whom dialysis is a better treatment option?  
Please Describe these kinds.
4. Are there certain kinds of patients for whom transplantation is a better treatment option? Please Describe these kinds.
5. Do you actively encourage patients to seek a kidney transplantation?  
1     ☐     Yes     --->What do you say that encourages them?  
2     ☐     No  
8     ☐     NR/NA
6. Do you actively encourage patients to seek living related-donors?  
1     ☐     Yes     --->What do you say that encourages them?  
2     ☐     No  
8     ☐     NR/NA
7. In what order do you present kidney treatment options to new ESRD patients?
8. Do you spend the same amount of time discussing each treatment option or do you emphasize one option more than the others?
9. For patients whose kidneys are progressively getting worse, how long before they start dialysis do you start talking about their treatment options?
10. Is there a physiological measure or patient symptom (creatinine, creatinine clearance) that keys you into the fact that the time has come to talk about their treatment options?
11. For patients whose kidneys have become end-stage suddenly, how long after they start dialysis do you usually begin talking about their treatment options and transplantation?
12. Do you ever tell patients how long people can live on dialysis compared to transplantation?

### Compliance issues

13. What does "compliance" mean to you?
14. How do you determine dialysis patients' compliance while on dialysis?
15. What are specific measurements that show a patient is compliant ?  

Normal                      Non-Compliant  
potassium levels  
phosphorus levels  
fluid gain  
blood pressure
16. Do patients ever have normal labs but are not compliant?
17. Are patients with non-normal labs ever really compliant?
18. How do nephrologists or other staff deal with patients who say they are compliant with their diet and medicines but their labs show otherwise?
19. How do you feel when patients do not "comply" with their medical regimen?
20. Have you ever noticed differences by ethnicity/race, gender, age in terms of compliance or non-compliance?
21. When a patient's first transplanted kidney was rejected due to non-compliance, do you think this patient should receive a second kidney?

### Patterns of Dialysis/Transplant Behavior

22. Do you have any patients who prefer not to have a kidney transplant? WHY?
23. Do you know any patients who have turned down an offered kidney? WHY?  
What about removing themselves from the waiting list?
24. What are reasons why ESRD patients do not want a living-related donor?

25. Have you noticed any patterns with regard to who donates to whom in families most often? (child to parent?/ sibs?)
26. How do you feel about multiple listing patients? Is it fair?
27. Do any of your patients use alternative medicines or do alternative therapies (yoga)? What do they do? How do you feel about them doing this?
28. I've spoken to patients who said that they were told to stay on dialysis for 1 year before the doctor would consider evaluating them for a transplant. Why do you think they are told this?

## Demographics

1. Respondent's sex:  
1 ☐ Male  
2 ☐ Female
2. How old are you?  
\_\_\_\_\_ years 8 ☐ NR
3. What is your race or ethnic heritage?  
1 ☐ White (of European descent) (Specify: \_\_\_\_\_)  
2 ☐ African American  
3 ☐ Asian  
4 ☐ Hispanic  
5 ☐ Native American  
6 ☐ Other (Specify: \_\_\_\_\_)  
8 ☐ NR
4. Do you belong to any formal religious denominations? If so, what denomination?  
1 ☐ Catholic  
2 ☐ Eastern Orthodox  
3 ☐ Protestant  
☐ Methodist  
☐ Presbyterian  
☐ Episcopalian  
☐ Baptist  
☐ Other  
4 ☐ Jewish  
☐ Reform  
☐ Conservative  
☐ Orthodox  
☐ Other  
5 ☐ Muslim  
6 ☐ Other (Specify: \_\_\_\_\_)  
7 ☐ No Denomination
5. Do you consider yourself a religious person?  
1 ☐ Yes  
2 ☐ No  
8 ☐ NR/NA
6. How important is religion in your life? Rate on a scale of 1 to 10, 10 being high:  
1 2 3 4 5 6 7 8 9 10  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
7. What is your marital status?  
1 ☐ Single  
2 ☐ Living with a Partner  
3 ☐ Married  
4 ☐ Divorced/Separated

- 5      ☐      Widowed
8.      In what year did you obtain your highest care-related degree?  
19\_\_\_\_
9.      What degree was that?
- 1      ☐      MD
- 2      ☐      Diploma/Associate Degree in Nursing
- 3      ☐      BSN
- 4      ☐      MSN
- 5      ☐      Other Bachelor's level degree
- 6      ☐      MA/MS/MPH/MSW
- 7      ☐      Ph.D.
- 8      ☐      Other (specify: \_\_\_\_\_)
- 88     ☐      NR/NA
10.     What kind of health care professional are you?
- 1      ☐      Physician
- ☐      Surgeon
- ☐      Nephrologist
- 2      ☐      Nurse/Transplant Coordinator
- 3      ☐      Social Worker
11.     How long have you been employed here in this position? \_\_\_\_\_

### **Appendix III: Transplant Professional Interview**

#### **Questions about Evaluating Patients for Transplantation**

1. What are the psychosocial & medical criteria you use to evaluate patients?
2. What are the most important hurdles that patients must jump over in the evaluations?
4. In what regards do you think that transplant departments at different hospitals vary in their criteria for evaluating patients for a kidney transplant?
5. Can you give me examples of patients' situations which you consider borderline patients acceptable for consideration of a transplant?

#### **Compliance**

6. How do you determine dialysis patients' compliance while on dialysis and with a transplant?
7. Have you ever noticed differences by ethnicity/race, gender, age in terms of compliance or non-compliance (while on dialysis)?
8. How much weight is given to compliance as a reason to not wait list a patient for a transplant?
9. Is 'patient motivation' an important issue, is that the case in your work? How can you tell they are motivated?
10. Do you think a patient's intelligence plays any role in how the transplant team evaluates patients?

#### **Drug use**

11. Does the transplant department expect patients with drug/alcohol or weight problems to go through a proven change (i.e., a drug program, lose weight) or sign a contract?
12. Do you test patients with a history of drug/alcohol use to make sure that they have stopped their habit?
13. Do you have them go through a drug program?
14. What about overweight patients?
15. Does this transplant center allow potential kidney recipients to smoke or drink alcohol?

#### **Turn downs/removals**

16. Do you know any patients who have turned down an offered kidney? WHY?
17. What about removing themselves from the waiting list?
18. Have you known any cases of patients removing themselves from the transplant waiting list?

#### **LRD**

19. What are reasons why ESRD patients do not want a living-related donor?
20. Have you noticed any patterns with regard to who donates to whom in families most often? (child to parent?/ sibs?)

#### **Finances**

21. How does the transplant team feel about transplanting patients who cannot pay for their medicines or surgery? Did you ever transplant patients like this?
22. What kind of role is financing the transplant and medications taking now in people's decisions to get a transplant?

#### **Misc.**

23. Is there an age limit here?
24. Is it important to know how patients originally got in contact with the transplant department?
25. When deciding whether to put patients on the waiting list, do you have any goals in mind, like, you want to put as many patients on the list as possible, or you want to put only the healthiest patients on the list, etc.?
26. What kinds of information about a donor kidney do the transplant surgeons or nurses tell the prospective recipient when they are called in for a transplant?
27. Are there any ways transplant professionals can get around or alter a patient's waiting time?
28. Did you ever have a policy for top medical priority for kidney patients, giving them urgent status? Why did it change?



29. How do you feel about multiple listing patients? Is it fair?
30. Do any of your patients use alternative medicines or do alternative therapies (yoga)? What do they do? How do you feel about them doing this?

### Demographics

1. Respondent's sex:
  - 1 ☐ Male
  - 2 ☐ Female
2. How old are you?
  - \_\_\_\_\_ years                      8 ☐ NR
3. What is your race or ethnic heritage?
  - 1 ☐ White (of European descent) (Specify: \_\_\_\_\_)
  - 2 ☐ African American
  - 3 ☐ Asian
  - 4 ☐ Hispanic
  - 5 ☐ Native American
  - 6 ☐ Other (Specify: \_\_\_\_\_)
  - 8 ☐ NR
4. Do you belong to any formal religious denominations? If so, what denomination?
  - 1 ☐ Catholic
  - 2 ☐ Eastern Orthodox
  - 3 ☐ Protestant
    - ☐ Methodist
    - ☐ Presbyterian
    - ☐ Episcopalian
    - ☐ Baptist
    - ☐ Other
  - 4 ☐ Jewish
    - ☐ Reform
    - ☐ Conservative
    - ☐ Orthodox
    - ☐ Other
  - 5 ☐ Muslim
  - 6 ☐ Other (Specify: \_\_\_\_\_)
  - 7 ☐ No Denomination
5. Do you consider yourself a religious person?
  - 1 ☐ Yes
  - 2 ☐ No
  - 8 ☐ NR/NA
6. How important is religion in your life? Rate on a scale of 1 to 10, 10 being high:
 

1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. What is your marital status?
  - 1 ☐ Single
  - 2 ☐ Living with a Partner
  - 3 ☐ Married
  - 4 ☐ Divorced/Separated
  - 5 ☐ Widowed
8. In what year did you obtain your highest care-related degree?
 

19\_\_\_\_

9. What degree was that?
- 1 ☐ MD
- 2 ☐ Diploma/Associate Degree in Nursing
- 3 ☐ BSN
- 4 ☐ MSN
- 5 ☐ Other Bachelor's level degree
- 6 ☐ MA/MS/MPH/MSW
- 7 ☐ Ph.D.
- 8 ☐ Other (specify: \_\_\_\_\_)
- 88 ☐ NR/NA
10. What kind of health care professional are you?
- 1 ☐ Physician ☐ Surgeon  
☐ Nephrologist
- 2 ☐ Nurse/Transplant Coordinator
- 3 ☐ Social Worker
11. How long have you been employed here in this position? \_\_\_\_\_

#### Appendix IV: Social Worker Interview

1. What is your role as a social worker?
2. What is the demography of this dialysis center?

#### Treatment Decisions

3. Why do patients want a transplant?
4. Why do patients not want a transplant?
5. Do patients ever say they feel uncomfortable with someone else's body part in them?
6. Do patients ever have religious reasons for not wanting a transplant?
7. Have you ever noticed differences by ethnicity/race, gender, age in terms of patients' decisions to seek a transplant or remain on dialysis?

#### Communication

8. Do you talk to patients about transplantation?
9. Do you ever actively encourage patients to seek a kidney transplantation?  
--->What do you say that encourages them?  
--->Are there people you don't encourage?

#### Turn down/Removal

10. What are reasons why patients turned down a kidney?
11. Have you known any cases of patients removing themselves from the transplant waiting list?

#### LRD

12. What reasons have you heard for why patients do not want a LRD?
13. What kinds of patterns have you seen most in who donates to whom? (LRD)

**Appendix V: Expected Remaining Lifetimes for US Population (1990), All ESRD Patients<sup>1</sup> (1996) and Dialysis Patients (1996) by Age, "Race" and Sex**

Age	US Population, 1990 <sup>2</sup>				ESRD Population, 1996 <sup>4</sup>				Dialysis Population <sup>3,4</sup> , 1996			
	"Black"		"White"		"Black"		"White"		"Black"		"White"	
	M	F	M	F	M	F	M	F	M	F	M	F
0-14	61.5	67.0	71.1	78.0	29.0	27.6	33.1	32.1	20.3	19.7	18.8	18.8
15-19	51.3	57.4	58.5	65.0	22.7	21.5	24.5	23.5	19.3	18.4	16.4	15.2
20-24	46.8	52.9	53.8	60.1	19.5	18.5	21.3	20.3	16.8	15.9	14.0	13.0
25-29	42.5	48.7	49.2	55.3	16.8	16.5	17.8	17.5	14.5	14.1	11.3	11.0
30-34	38.2	44.6	44.6	50.4	14.6	14.5	15.0	14.9	12.7	12.5	9.4	9.3
35-39	34.1	40.6	40.0	45.6	12.8	12.8	12.6	12.6	11.3	11.4	8.0	7.9
40-44	30.1	36.8	35.4	40.8	11.1	10.9	10.5	10.6	10.0	9.8	6.9	7.1
45-49	26.2	32.4	30.9	36.1	9.4	9.3	8.7	8.7	8.6	8.5	6.1	6.3
50-54	22.5	28.2	26.5	31.5	7.9	7.7	7.1	6.9	7.3	7.1	5.2	5.2
55-59	19.1	24.3	22.4	27.0	6.7	6.6	5.6	5.6	6.3	6.3	4.4	4.5
60-64	16.0	20.6	18.6	22.8	5.5	5.5	4.4	4.5	5.2	5.3	3.7	3.9
65-69	13.3	17.2	15.2	18.9	4.4	4.5	3.5	3.6	4.2	4.4	3.1	3.3
70-74	10.8	14.2	12.0	15.2	3.6	3.7	2.9	3.0	3.5	3.7	2.7	2.9
75-79	8.8	11.3	9.3	11.8	2.9	3.0	2.4	2.5	2.9	3.0	2.4	2.5
80-84	6.9	8.7	7.0	8.8	2.5	2.5	2.1	2.1	2.5	2.5	2.1	2.1
85+	5.4	6.5	5.1	6.1	2.1	2.0	1.7	1.7	2.1	2.0	1.7	1.7

1 Includes patients treated with either dialysis or transplantation.

2 Vital Statistics of the US, Vol 2, 1990: Mortality, Part A, Table I-9.

3 Mortality followup is censored at transplant.

4 Death rates for these calculations exclude dialysis unrelated deaths.

Source: USRDS 1998.

## Appendix VI: List of Dialysis Patients and Dialysis and Transplant Professionals

### Pro-Transplant Patients

<i>African American</i>	<i>European American</i>	<i>Malaysian</i>
Jonnie	Rosa	Fatima
Jan	Ben	
Luke	Raymond	<i>Lebanese</i>
Simon	Mindy	Sofia
Noah	Maureen	
Clarence	Sandy	
Emmanuel	Gina	
Ginnie	Scott	
Bruce	Jerry	
Louise	Annette	
Samuel	Fred	
Jerome	Dennis	
Pearl	Danielle	
June	Richard	
Monique	Paige	
Joshua	Warren	
Albert	Irving	
Wilma	Henry	
Talmadge	Arthur	
Chantal		
Roy		
Douglas		
Tammy		
Mark		
Brendan		
Hazel		
Allison		
Joseph		

### Con-Transplant Patients

<i>African American</i>	<i>European American</i>
Naomi	Juliet
Roger	Cecelia
Carl	Elaine
Pauline	Edward
Marshall	Meredith
Clifford	Clare
Michael	
Virginia	
Dorothy	
Beverly	
Francine	
Janet	
Audrey	
Roland	
Donna	
Gloria	
Lewis	
Georgia	
Shirley	
Anthony	
Barbara	
Andrew	
Malcolm	
Elliot	

\*\*\*

Dialysis and Transplant Professionals

at AH:

Dr. Benton	Head Transplant Surgeon
Dr. Riley	Transplant Surgeon
Dr. Julian	Head Transplant Nephrologist
Dr. Ingel	Transplant Nephrologist
Dr. Gilmore	Head Hemodialysis Nephrologist
Dr. Olson	Dialysis Nephrologist
Dr. Easton	Dialysis Nephrologist (Hemodialysis and Peritoneal dialysis)
Dr. Lock	Head Peritoneal Dialysis Nephrologist
Lorna	Head Transplant Coordinator (RN)
Kathy	Transplant Coordinator (RN)
Nancy	Transplant Coordinator (RN)
George	Transplant Social Worker
David	Transplant Social Worker
Rose	Transplant Medical Secretary
Joanne	Dialysis Social Worker

Elsewhere:

Dr. Mori	Dialysis Nephrologist, established CDCs
Dr. Alland	Transplant Nephrologist
Dr. Varga	Dialysis Nephrologist
Dr. Young	Dialysis Nephrologist
Dr. Testa	Head Dialysis Nephrologist
Dr. Avi	Head Dialysis Nephrologist
Dr. Nicola	Head Dialysis Nephrologist
Debbie	Dialysis Social Worker
Erika	Dialysis Social Worker
Brian	Dialysis Social Worker
Monica	Dialysis Social Worker
Theresa	Dialysis Social Worker

**Appendix VII: Categorization of Dialysis Patients' Professional, Service, Business, and Labor Occupations**

**Professional (requires certification, degree, credentials)**

Designs x-ray machines  
Corrections Officer  
Corrections Officer  
Deputy Sheriff  
Accountant  
Engineer  
Teacher in Special Education  
Lawyer

**Service**

City Treasurer  
Nurse's Aid  
Nurse's Assistant  
Day care Provider  
Child care  
Cashier  
Sales  
Market Bagger  
Community Organizer, Health Advocate

**Business**

Systems Finalizing  
Award Advertising  
Receptionist  
Secretary

**Labor**

Foreman  
Construction Electrician  
Manages Apartment Building

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